

Toxic Information: Handle With Care



Nancy S. Wexler

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and

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40+

years
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Disease
Foundation
Innovation
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Huntington's disease



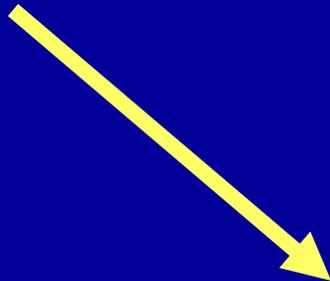
Chromosome 4



...CAG CAG CAG...



Normal Protein



...CAG CAG CAG CAG CAG CAG CAG...



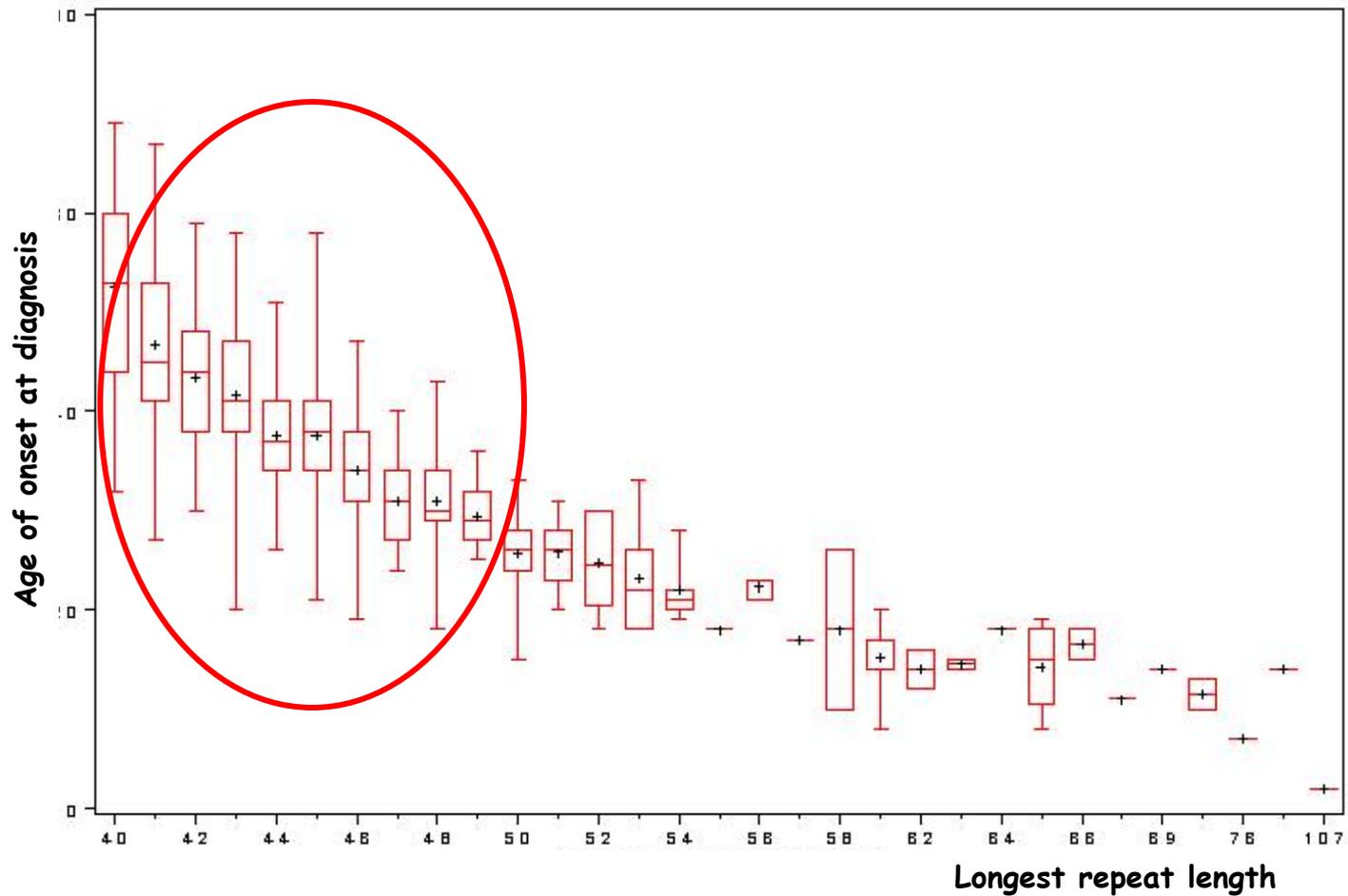
Abnormal Protein

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Age of Onset



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GUIDELINES FOR THE MOLECULAR GENETICS PREDICTIVE TEST IN HUNTINGTON'S DISEASE (NEUROLOGY 1994;44;1533-1536)

TESTING GUIDELINES

Recommendations

1. All individuals who may wish to take the test should be given up-to-date, relevant information so that they can make an **informed, voluntary decision**.

Comments

1. Counseling of the highest standards should be available in each country. It is recommended that, as a standard medical practice, informed consent for the test be documented with the signature of the person to be tested and the professional responsible for the counseling.

TESTING GUIDELINES, cont'd.

Recommendations

2. The decision to take the test is **solely the choice of the individual** concerned. No requests from third parties - family members or otherwise - shall be considered.

Comments

2. The individual must choose freely whether to be tested and must not be coerced by family, friends, partners or potential partners, physicians, insurance companies, employers, governments or others.

TESTING GUIDELINES, cont'd.

2.1 The test is available only to individuals who have reached the age of majority (according to the laws of the respective country).

2.1 A prenatal test may constitute an exception to this rule. Testing for the purpose of adoption should not be permitted, since the child to be adopted cannot decide for himself or herself whether to be tested. It seems appropriate and even essential, however, that the child be informed of his or her at-risk status upon reaching the age of reason.

TESTING GUIDELINES, cont'd.

2.2 Each participant should be able to take the test regardless of his or her financial situation.

2.2 Each national lay organization should use its influence with government departments, public & private health insurers, & other organizations to reach this goal.

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TESTING GUIDELINES, cont'd.

2.3 Individuals should **not be discriminated against** in any way as a result of genetic testing for HD.

Prenatal genetic diagnosis = PDG

Catastrophic Events after HD Predictive Testing

118/178 centers from 21/26 countries participated in a survey.

44/6,363 individuals experienced a catastrophic event (CE) after receiving predictive testing results

- 5 individuals committed suicide
- 19 individuals attempted suicide
- 20 individuals were hospitalized for psychiatric reasons

Almqvist et al 1998

Of those with a catastrophic event:

80% had an expanded *CAG* repeat

20% had a normal *CAG* repeat size

50% were symptomatic when the catastrophic event occurred

The catastrophic event usually occurred within the first year after receiving presymptomatic test results

A history of previous psychiatry problems was associated with later catastrophic events

Approximately 2/3 of all test centers worldwide may still underestimate the true frequency of CE.

The Genetics and Public Policy Center
05/28/2010 compiled data of
Direct-to-Consumer Genetic
Testing Companies and the tests
they offered.

There are now 31 companies offering
genetic tests on ~450 *diseases,*
genes & traits including:

- Affectionate gene*
- Aging
- Alcohol Flush Reaction
- Alzheimer's disease*
- Ashkenazi Jewish Screening
- Athletic Performance
- Attentiveness/Focused Gene*
- Avoidance of Errors
- Back Pain
- Birth Weight
- Breastfeeding and IQ
- Cigarette Injury*
- Comprehension Gene *
- Creative Gene *
- Dancing Gene *
- Detoxification Capacity*
- Drawing Gene *
- Endurance Gene*
- Explosive Power Gene*
- Eye Color
- Faithfulness/Loyalty Gene *
- Fat Intake and BMI
- Fatigue
- Fetal Gender
- Food Preference
- Freckling/Freckles
- General Wellness Gene *
- Hair Color
- Hair Thickness
- Height
- Heroin Addiction
- Impulsive Gene*
- Intelligence Gene *
- Kaposi Sarcoma in HIV Infection
- Linguistic/Literature Gene*
- Longevity
- Measures of Intelligence

- Memory/Episodic Memory Performance*
- Memory of Older People
- Metabolic Health
- Mould-ability/Adaptability Gene*
- Muscle Explosiveness
- Muscle Performance
- Musical Gene*
- Nicotine Dependence
- Odor Detection
- Optimal Health Test
- Optimism Gene*
- Pain Sensitivity
- Passion/Enthusiasm Gene*
- Performing Gene*
- Persistence Gene*
- Poison Activation Capabilities*
- Propensity for Teenage Romance Gene *
- Recurrent Pregnancy Loss
- Response to Viagra
- Risk Taking Gene*
- Schizophrenia*
- Self Detoxifying Gene*
- Sensitivity (or Insensitivity) to Second-Hand Smoke Gene*
- Sensitivity/Sentimentality Gene*
- Shyness Gene*
- Skin Color
- Skin Profile
- Smoking Gene*
- Sociable Gene*
- Split Personality Gene*
- Sports and Training Test
- Technique/Skill Gene*
- The Effect of Antidepressants
- Weight Management

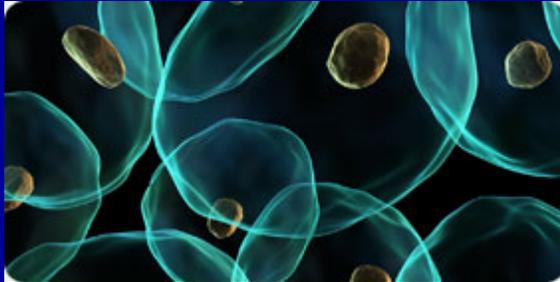
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Talent Test

The **Inborn Talent Genetic Test** reveals the inherited and endowed inborn talents of a child scientifically from the genetic makeup of his/her DNA. The test result will therefore help parents identify their children's hidden talents that may not be obvious at young age.

Furthermore, it also reveals some personality traits that the child may possess, judging from his/her genetic make-up.

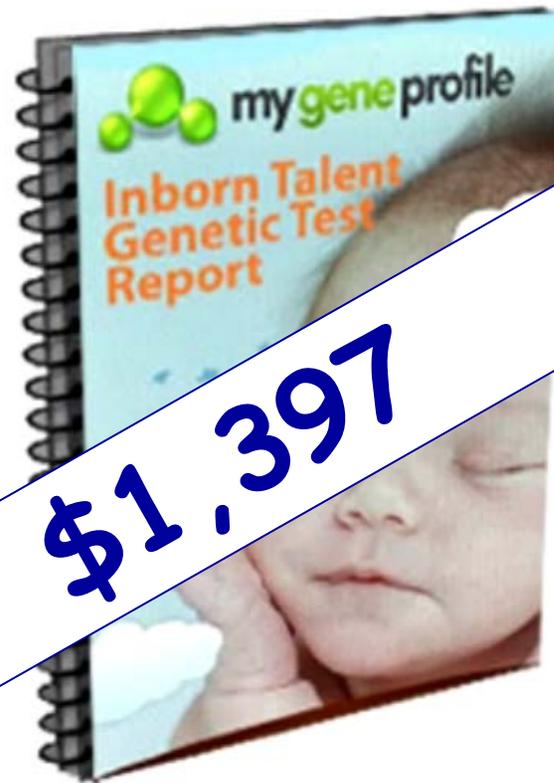
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\$1,397

Picture is for illustration purpose only

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www.mygeneprofile.com/gene

- * Unconsciously forcing your child into doing what he/she dislikes
- * Have no idea what he/she likes
- * Unwanted argument with your child
- * Unable to make the right decision for your child's education

01:36 15:10

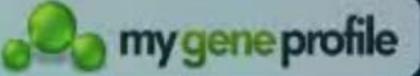
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1. 99.8% Accuracy
2. Top American Technology
3. Certified Labs
4. For ALL Ethnicities
5. 100% Safe Testing Procedures
6. Confidentiality Assured
7. HIGHEST number of genes tested



If you want to STOP RISKING YOUR LIFE, please read this important letter...

**Are You Worried Your Genes May Be Defective...
Do You Ever Wonder If You Could Be Susceptible to a
*Hereditary Disease? Protect Your Precious Life!***

From the desk of: Dr. John Sebastian, M.D.

Dear Health Conscious Friend,

Right now your or your child body's genes could be *hiding a time bomb...* but how would you know?

You wouldn't know would you? Even your doctor doesn't know.

How can anyone predict what their real medical health may be like in a few years time?

But as a health conscious person, it's your responsibility to *know so you can help your doctor prevent future health problems. You will face life threatening problems from the genes you inherited from your parents, grand parents and even great grandparents!*

You may be taking the best care of your health you can, but how to you prevent serious health problems from diabetes, heart attack and stroke?

I bet you thought you can't...



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***Prevention is Better Than Cure.
BUT DO YOU TAKE ANY ACTION ON IT ?***

You can be an incredibly healthy person but you need to know your Health Genetic Profile now so you can take the best care of your health you can. If you want vibrant health, you need to know your inherited genetic health risk. With the Disease Susceptibility Genetic Test, *you can know how to avoid situations and stresses that can cause these dreaded diseases to develop.*

The Disease Susceptibility Genetic Test is available for you to take today. This is thanks to the world class genetic scientists who worked on the Human Genome Project and the countries who poured billions of dollars in genetic research. These elite scientists uncovered the secrets behind genes, DNA and gene mapping. Because of this in-depth gene mapping knowledge we can determine your inherited health risks.

Take advantage of Disease Susceptibility Genetic Test in order to take the guess work out of making your health related decisions.

Testing is performed by certified laboratories in the US & Asia.
Laboratories are certified with *GLP, GCP, GMP* and are *CLIA* compliant.

Partners include *GlaxoSmithKline, Eli Lilly, Merck Sharp & Dohme(MSD)* and *Pfizer*.

OVERVIEW OF THE 108 TYPES OF DISEASE & PERSONALITY GENES:

Respiratory

Acute (recurrent)
Bronchitis Acute Bronchitis
Bronchial Asthma
Bronchial Pneumonitis
Bronchitis
Chronic Obstructive Pulmonary
Disease
Emphysema
Laryngeal Cancer
Lung Cancer
Nasopharyngeal Cancer
Non Small Cell Lung Cancer
Obstructive Emphysema
Pneumothorax
Pulmonary Tuberculosis
Recurrent Pneumonia
Sleep Apnea Syndrome
Rheumatic Heart Disease

Circulatory

Acute Lymphoblastic Leukemia
Atherosclerosis
Auricular Fibrillation
Anemia
Cardiomyopathy
Chronic Lymphoblastic
Leukemia
Coronary Atherosclerotic Heart
Disease
Diabetic Angiocardopathy
Heart Failure
Henoch Schonlein Purpura
Hyperlipidemia
Hypertrophic Cardiomyopathy
Hypertension
Hypoglycemia
Myocardial Infarction

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Musculo-skeletal + Skin

Bone Cancer
Gout
Osteoporosis
Polymyalgia Rheumatica
Polymyositis /
Dermatomyositis
Psoriasis
Rheumatoid Arthritis
Skin Cancer

Cerebral / Nervous / Neuro

Cerebral Infarction (young)
Cerebral Infarction
Child Epilepsy
Migraine
Multiple Sclerosis
Parkinson's Disease
Senile Dementia (Alzheimer's
disease)
Subarachnoid Hemorrhage
Stroke
Transient Ischemic Attack

Urinary

Acute Glomerulonephritis
Bladder Cancer
Cholecystitis
Cholelithiasis
Diabetes Nephropathy
Gallbladder Cancer
Lupus Nephritis
Nephrotic Syndrome
Nephritis
Renal Cancer
Type I Diabetes Mellitus I
Type II Diabetes Mellitus
(with Microvascular Disease)
Type II Diabetes Mellitus II

Reproductive

Breast Cancer
Cervical Cancer
Endometriosis
Endometrial Cancer
Hysteromyoma
Ovarian Cancer
Ovarian Tumor
Prostate Cancer
Prostate Hyperplasia

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Liver

Alcoholic Cirrhosis
Autoimmune Hepatitis
Chronic Hepatitis Type B
Liver Cirrhosis
Fatty Liver
Liver Fibrosis (Hepatitis C)
Non Alcoholic Fatty Liver
Primary Biliary Cirrhosis
Primary Carcinoma Of The Liver

Immune + Sensory

Cataract
Glaucoma
Hearing Impairment
Hypothyroidism (myxedema)
Lymphoma
Systemic Lupus Erythematosus
Thyroiditis
Thyroid Cancer

Digestive

Acute Pancreatitis
Stomach Cancer
Chronic Gastritis
Chronic Pancreatitis
Colorectal Cancer
Crohn Disease
Duodenal Ulcer
Esophageal Adenocarcinoma
Esophagitis
Esophageal Cancer
Familial Adenomatous Polyposis
Coli (with Multiple Tumour
Syndrome)
Gastric Ulcer
Inflammatory Bowel Disease
Irritable Bowel Syndrome
Oral Cancer
Pancreatic Cancer
Polyposis Colon
Reflux Esophagitis
Ulcerative Colitis

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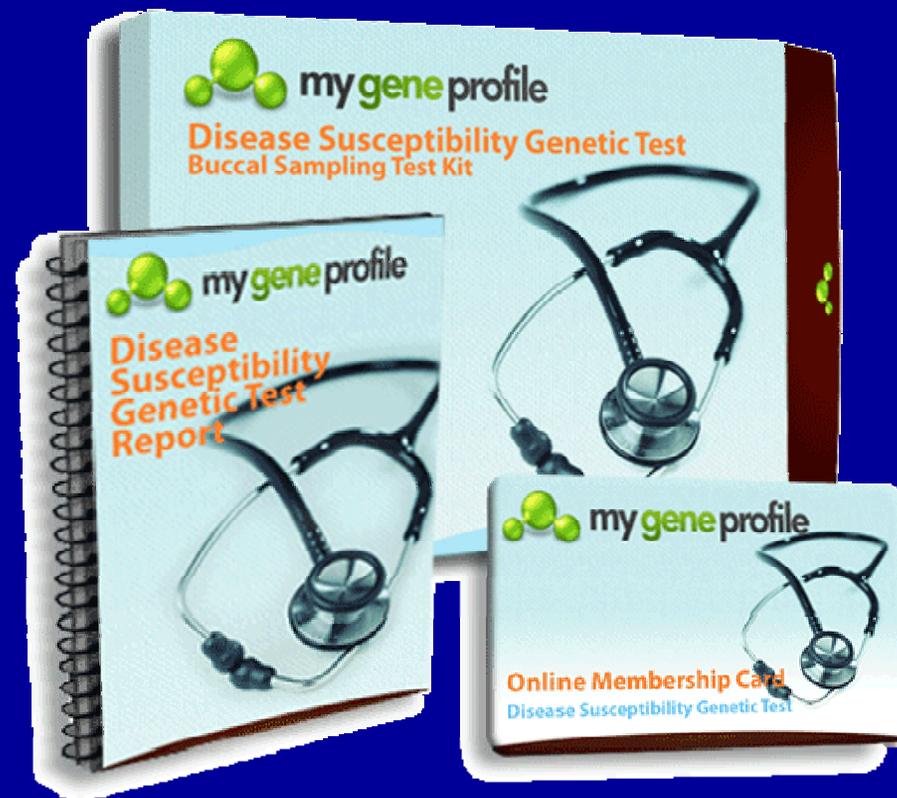
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My Gene Profile's Disease Susceptibility Genetic Test Complete Package



TOTAL VALUE: \$18,877

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And the GOOD News is:

During this Global Product Launch,
you can get the Complete Disease
Susceptibility Genetic Test
for **ONLY \$1,897** ~~\$18,877~~ ~~— \$2,997~~

Genetic Cancer Scan Testing Kit offered on Amazon.com for \$12.99 (\$639 lab fee not included)

Amazon.com: Genetic Canc... x

www.amazon.com/Identifies-carcinomas-features-Included-Features/dp/B002IT3ZI0/ref=sr_1_1?ie=UTF8&qid=1299085899&sr=8-1

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Prime This item is not eligible for Amazon Prime when purchased from Viaguard, Inc. [See more buying choices](#)

Member: Julie Porter

VIAGUARD
Genetic Cancer Scan
Easy to Use At Home Sample Collection Kit

Submit Swabs of Your Inside Cheeks to our Lab
Confidential Report in 25 days

Understanding Risk
Empowering Prevention by Early Detection

Identifies genetic variants linked to the following carcinomas:

- Breast Cancer
- Skin Cancer
- Lung Cancer
- Colorectal Cancer
- Bladder Cancer
- Prostate Cancer
- Thyroid Cancer

Lab processing fee of \$639 not included.
Lab fee is payable only when samples are submitted for analysis.

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Genetic Cancer Scan Testing Kit. Identifies genetic variants linked to carcinomas as listed in key product features. Lab Fees Not Included. See Key Product Features.
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Price: **\$12.99**

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\$12.99 + \$4.74 shipping
In stock. Processing takes an additional 4 to 5 days. Sold by **Viaguard, Inc.**

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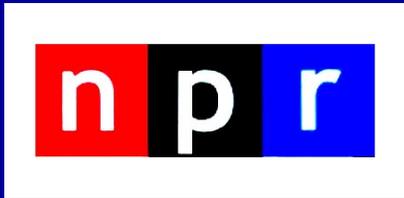
Share [Email](#) [Facebook](#) [Twitter](#)

Product Features

- Identifies genetic variants linked to below carcinomas
- Breast Cancer, Skin Cancer, Lung Cancer, Thyroid Cancer
- Colorectal Cancer, Bladder Cancer, Prostate Cancer
- Lab Fee of \$639 not included
- Lab Fee payable only when samples submitted

Genetic Testing Companies Busted By Undercover Patients

by ALLISON AUBREY, July 22, 2010



With so much uncertainty and concern about how the sum of the genes in our DNA will affect our health, there's plenty of room for companies claiming to have the answers to take advantage of our fears.

Will I have a heart attack? Am I at risk for prostate cancer? Clues may lie in our genetic code. At the moment, though, general genetic tests can't say for sure whether *you* will develop many common diseases.

Unfortunately, this scientific muddle hasn't stopped some companies selling genetic testing services directly to consumers from making overblown and misleading claims about them.

The Food and Drug Administration has been looking into the developing industry. And today congressmen grilled several company execs in a Capitol Hill hearing that featured some explosive revelations about claims made to undercover investigators.

The bombshell at the hearing was the unveiling of results of an undercover investigation by the Government Accountability Office that found some pretty startling claims being made by the companies.

THE LANCET

The ethics of direct-to-consumer genetic testing

The US Government Accountability Office has labelled them misleading, but personal genetic tests continue to grow in popularity. Laurie Udesky looks at the ethical issues involved.



The NEW ENGLAND
JOURNAL of MEDICINE

Risks of Presymptomatic Direct-to-Consumer Genetic Testing

Justin P. Annes, M.D., Ph.D., Monica A. Giovanni, M.S., C.G.C.,
and Michael F. Murray, M.D.

N ENGL J MED 363:12 NEJM.ORG SEPTEMBER 16, 2010



Walgreens to Sell OTC Genetic Testing Kits

Kit offers info on genetic inclination to illness

By MATT BARTOSIK, 12:30 PM CST, Tue, May 11, 2010

Market Press Release

March 1, 2011 11:20 am –

Sports DNA Test in India -

DNA test helps to choose the
right sport.



AMA to FDA: Genetic Testing Should Be Conducted by Qualified Health Professionals

For immediate release: Feb. 23, 2011

Bloomberg Businessweek

MEDICAL DEVICES February 24, 2011, 5:00PM EST

There's Already a Doctor in the House

Dozens of over-the-counter
tests allow consumers to play
doctor at home

FOREST PARK

Tuesday, February 08, 2011

Ethics of genetic testing

*Lecture at Loyola looks at
realities of over-the-counter
genetic tests*

By **JEAN LOTUS**, Contributing Writer



genome.gov

National Human Genome Research Institute

National Institutes of Health

Ethical, Legal and Social Implications of Human Genome Research

Task Force on Promoting Safe and
Effective Genetic Testing in the USA

Final Report: September 1997

Task Force Recommendations

No clinical laboratory should offer a genetic test whose clinical validity has not been established

Unless it is collecting data on clinical validity under either an IRB-approved protocol or conditional premarket approval agreement with FDA.

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Recommendations, cont'd.

Tests that can be used for purposes of predicting future disease be given a rating of high complexity.