

Media Resources & Tips

We're on the brink of a new era of personalized, gene-based medicine. Are we ready for it? The Hastings Center, the nation's foremost bioethics research institution, has partnered with PBS's NOVA to produce an hour-long documentary and related resources that address this critical issue.

The TV Documentary

Airs Wednesday, March 28, on PBS

What will it mean when many of us can afford to have the information in our DNA—all 3.1 billion chemical letters of it—read and available for analysis? Cracking Your Genetic Code reveals that we stand on the verge of such a revolution. Meet doctors, patients, and ethicists who are grappling with the promises and the pitfalls of this new era in medicine. Advanced technologies and designer drugs may save countless lives, but they also raise moral dilemmas: Will it help or hurt us to know the diseases that may lie in our future? What if such information falls into the hands of insurance companies, employers, or prospective mates? One thing is certain: gene-based medicine will profoundly impact individual lives and our society as a whole. Following the initial broadcast, which starts March 29, the full program will stream online at www.pbs.org/nova/body/cracking-your-genetic-code.html.

Genetic Testing Dilemmas:

Four Role-Playing Scenarios

www.pbs.org/nova/body/genetic-testing-dilemmas

This interactive Web feature takes you through four scenarios that touch on the complex practical and emotional issues of genetic tests. At the beginning and at the end of each scenario, you make a choice—YES, NO, or UNSURE—about whether you would get tested. In addition to exploring the issues, you can see what others who take the poll chose to do.

- Scenario 1: Should you test your embryos for gene mutations before having a baby?
- Scenario 2: Should you ask your doctor for a genetic test, or order a direct-to-consumer test, that can offer some idea of your risk for contracting Alzheimer's disease later in life?
- Scenario 3: You have a family risk of breast cancer. Should you ask your doctor about getting your genes tested for mutations that increase your risk?
- Scenario 4: Should you get a direct-to-consumer genetic test to help take control of your health?

Tips for Using This Resource:

As in real life, there are no right or wrong answers in these role-playing exercises. Each person has unique preferences, experiences, and needs. These scenarios may help individuals think through their own feelings as well as understand the feelings of others—physicians, patients, and family members. You can use them as a springboard for reflection and discussion. It may be helpful to jot down notes as you go through the feature to use in such discussions. You can also try adopting different perspectives (e.g., as a parent, a caretaker, a friend).

ADDITIONAL NOVA RESOURCES

Public Genomes (13-minute video)

(This and other NOVA videos listed below are available to stream online.)

This 2009 NOVA scienceNOW segment investigates commercial DNA testing.

www.pbs.org/nova/body/public-genomes.html

Epigenetics (13-minute video)

Explore how environmental factors can alter gene expression, making even identical twins different.

www.pbs.org/nova/body/epigenetics.html

Autism Genes (13-minute video)

See how researchers have begun to zero in on genes that might be responsible for autism.

www.pbs.org/nova/body/autism-genes.html

Cracking the Code of Life (two-hour video)

This 2001 program chronicles one of the greatest milestones in science: decoding the human genome.

www.pbs.org/nova/body/cracking-the-code-of-life.html

Personal DNA Testing: Expert Q&A (text)

Harvard geneticist Rudy Tanzi offers caveats about commercial DNA testing.

www.pbs.org/nova/body/tanzi-genetic-tests.html

Ethics of Manipulating Genes (text)

Philosopher Philip Kitcher discusses the moral and ethical implications of molecular medicine.

www.pbs.org/nova/body/ethics-of-manipulating-genes.html

Four DNA Tests (interactive & poll)

Learn about prenatal testing, gene sequencing, SNP testing, and genome sequencing.

www.pbs.org/nova/body/genetic-testing.html

Journey into Human DNA (interactive)

This animated feature can help laypeople understand the basic structure of DNA.

www.pbs.org/nova/body/journey-into-human-dna.html

THE HASTINGS CENTER RESOURCES

Help with Hard Questions

A new question-and-answer consumer Web site designed to help people think through genetic testing and other health care decisions in a way that is consistent with their values.

www.hastingshardquestions.org

Genetic Testing and Screening

Learn about common forms of genetic analysis, including prenatal screening and DTC genetic testing.

www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2176

Personalized Medicine and Genomics

Explore the complexities of genetically based health care, risk assessment, and more.

www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2200

Biobanks: DNA and Research

Find out how stored biological specimens can be used in genetic and biomedical research.

www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2154

OTHER RECOMMENDED RESOURCES

GeneTests

www.genetests.org

A publicly funded medical genetics information resource for health care providers and researchers. It includes educational materials about the appropriate use of genetic counseling and testing.

Collins, Francis S. 2010. *The Language of Life: DNA and the Revolution in Personalized Medicine*. HarperCollins.

Davies, Kevin. 2010. *The \$1,000 Genome: The Revolution in DNA Sequencing and the New Era of Personalized Medicine*. Free Press.

Green, Ronald M. 2007. *Babies by Design: The Ethics of Genetic Choice*. Yale University Press.

Klitzman, Robert L. 2012. *Am I My Genes?* Oxford University Press.

Zallen, Doris Teichler. 2008. *To Test or Not to Test: A Guide to Genetic Screening and Risk*. Rutgers University Press.

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DAVID H. KOCH

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We never forget who we're working for

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