

2009 First Year Reading Program Facilitator's Guide

Dear First Year Reading Program Facilitator,

Welcome to **F**irst Year **R**eadin**G** **P**rogram (FYR) 2009. We are glad to have you with us and certainly appreciate you taking the time to help with this program designed to introduce our newest JMU class to academic life at JMU.

Personnel from Student Affairs and Academic Affairs partner to engage our newest class with a challenging text, and to facilitate critical thinking prior to and after students' arrival in the classroom. The partnership (Orientation, General Education and Libraries) starts with text selection and continues through the summer, as we plan for the facilitated sessions and First Year Convocation. It's not just about Orientation or reading the assignment; it's about helping incoming students connect the dots from the Orientation experience to the classroom, from the classroom to their own lives and experiences, and the role they will play at JMU by asking questions and creating knowledge.

Typically, FYR programs assign a book for students to buy and read, but at JMU we do first year reading a little differently than other campuses. This year's text selection is indicative of that. Faced with a budget crisis, the FYR Planning team was challenged to find an online, publicly available text that would incur no or little production costs. *The DNA Age* fit the bill. *The DNA Age* is a series of articles that appeared in the New York Times from 2006-2008 and won a Pulitzer Prize for Explanatory Reporting in 2008 for reporter Amy Harmon. The original series consisted of 16 articles that appeared from April 2006-October 2008. We've selected nine of the sixteen as the FYR text for this year. We've asked the incoming students to read these nine articles:

- Facing Life with a Lethal Gene
- Stalking Strangers' DNA to Fill in the Family Tree
- Prenatal Tests Puts Down Syndrome in Hard Focus
- As Breeders Turn to DNA Tests, Dogs Become Guinea Pigs
- Cancer Free at 33, but Weighing a Mastectomy
- Seeking Columbus's Origins, with a Swab
- In DNA Era, New Worries about Prejudice
- My Genome, Myself: Seeking Clues in DNA
- After DNA Diagnosis: "Hello, 16p11.2. Are You Just Like Me?"

Estimated reading time for all the assigned articles 40 minutes to an hour.

This series of articles contemplate big questions that can be tackled as a whole, or broken down to view through the lens of a specific discipline. So while some may be more comfortable facilitating a general conversation about what it means to be human, identity formation or scientific literacy, others might be more comfortable discussing one or two articles that relate more to a specific discipline. This facilitators' guide is designed with to work in either setting. But, please remember, FYR isn't about teaching the material (there isn't a test!) it's about setting the stage. At JMU, we read, we think about what we read, and we work with content in order to inform our understanding.

While the articles are available on the public internet at the Pulitzer's website (<http://www.pulitzer.org/works/2008-Explanatory-Reporting>) we've pointed the students (and you) to a place on the Libraries' website to get the articles. This way we could ensure access even if the content disappeared off the public web. Also you will find easily printable, PDF versions of the articles in case you want to take them to your session.

On Thursday August 20 (2-3:30PM), you will have 90 minutes to facilitate a conversation with a group of students who are grouped by their residence halls and led by a FROG (First Year Orientation Guide) to your assigned room. In order to help you start the conversation, we asked faculty from all over campus to draft some sample ways to approach the articles. We've compiled their approaches to the text as a way of assisting those who might be a bit intimidated by the content or to serve as springboard to spark your own good ideas about how to approach the content with our newest class of students. Feel free to use or adapt their ideas during your session. We hope you find it useful. Our thanks to the faculty who contributed to the guide (Erica Clarke, Jim Mazoue, Michael Klein, Jennifer Sosnowski, Taz Daughtery, and Carol Hamilton).

You should know that the FYR experience doesn't end after your conversation ends. At first year Convocation (Sunday, August 23) the students will be engaged in programs revisit the FYR experience; we will explore the issues with a scenario designed to get the students to think critically as they role play "real life." It's a powerful and engaging experience to work with all 4000+ first year students all at once, but it's worth a look if you have the time to join us. We also encourage faculty and staff who work with first year students to engage them either in your class or just in conversation about their experiences with *The DNA Age*.

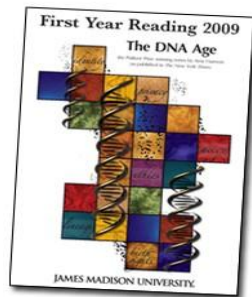
Thank you for your participation in this important First Year Program. If you have suggestions for future text selections or ideas about how to improve the FYR Program, we'd love to hear from you.

Tisha McCoy-Ntiamoah
Orientation

Gretchen Hazard
General Education

Kathy Clarke
Librarian





The **DNA AGE**

Assigned Article Summaries

Facing Life with a Lethal Gene

If you could know at age 23 that you would die from an inherited gene would you be tested? This is the story of a young woman who chose to know and how she is living with her genetic future.

Stalking Strangers' DNA to Fill in the Family Tree

Cheap and widely available genetic tests can reveal familial relationships; a godsend to amateur genealogists who go to great lengths to obtain samples from the willing and not-so-willing.

Prenatal Tests Puts Downs Syndrome in Hard Focus

“About 90 percent of pregnant women who are given a Down syndrome diagnosis have chosen to have an abortion.” Harmon, 2007. Is the “cure” for Downs the elimination of fetuses with the gene?

As Breeders Turn to DNA Tests, Dogs Become Guinea Pigs

Man’s best friend can currently be bred to fast, non-shedding and smart. With human genetic engineering on the horizon, could we be looking at the creation of designer humans?

Cancer Free at 33, but Weighing a Mastectomy

If you could reduce your chances for breast cancer but had to surrender your breasts and ovaries at 33 to do it, would you? One woman’s story as she grapples with life with a breast cancer gene that killed several of her relatives.

Seeking Columbus’s Origins, with a Swab

What if you found out that Bob Marley wasn’t Jamaican, but Canadian at least according to his DNA? DNA testing of the dead allows us to find out more about them and their lives, but should it change their legacy?

In DNA Era, New Worries about Prejudice

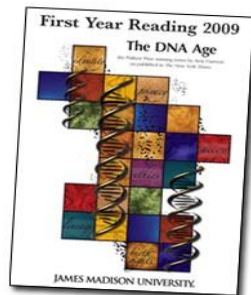
What if genetic research indicated that one ethnic group was predisposed to be “smarter” than another group?

My Genome, Myself: Seeking Clues in DNA

Loaded with your DNA for-profit websites can tell you whether you are likely to develop cancer or why you might hate milk. How much of you is genetically hardwired?

After DNA Diagnosis: “Hello, 16p11.2. Are You Just Like Me?”

Genetic defects, once attributed to personality or behavior disorders, are now diagnosable – even when the defect is rare. Families with children with genetic defects are finding each other and creating support groups and redefining the term family.



The DNA AGE

Companion to the Readings and Facilitator Guides

Issue #1: What does it mean to be human and should humans mess around with that?

All the articles in the series touch on some aspect of our humanity. Potential big picture topics for discussion include difference vs. similarity, biodiversity - when should we tinker with it or are we fast-tracking evolution. While much of the series revolves around the enormous strides being made to improve human health, there are places in the readings that make one wince with “what if” scenarios. It’s an easy jump to imagine genetic information in the hands of those who would use such technology for less than altruistic purposes. How does a society respond when the science gets ahead of its law and policy? What does history tell us about our ability to digest medical breakthroughs?

Consider humanness through a particular lens, how has art, literature, music or film depicted humanness throughout the ages?

Guides	Applicable Disciplines	Related <i>DNA Age</i> Articles
Prenatal & Newborn Screening	Philosophy & Religion, Sciences,	<i>Prenatal Test Put Down Syndrome in Hard</i>
Stem-Cell Research	Justice Studies, Political Science,	<i>Focus</i>
Genetic Engineering Advances or Bio-Divide?	ISAT, Business, Military Science,	<i>Facing Life with a Lethal Gene</i>
Business of Genetic Testing	English, Art & Art History,	<i>Cancer Free at 33, but Weighing a Mastectomy</i>
Consumer Genomics	Sciences	<i>As Breeders Test DNA, Dogs Become Guinea Pigs</i>

Issue #2: Scientific Literacy, Decision-Making, and Probability

How do we learn about scientific topics even if we are not scientists? How much science does the “average Joe” need? How and where does it he get it? Who is qualified to explain science? How does a society likely to be inundated with scientific information over the course of a human lifespan going to ensure a reasonably educated populace? Who defines what scientific literacy is? What are the consequences of scientific illiteracy?

Guides	Applicable Disciplines	Related <i>DNA Age</i> Articles
Deliberate Deception	Education, All Sciences, Social	<i>Facing Life with a Lethal Gene</i>
Scientific Rhetoric	Work, Economics, Writing Rhetoric	<i>Cancer Free at 33 but Weighing a Mastectomy</i>
Prenatal & Newborn Screening	and Technical Communication, Math	<i>My Genome, Myself</i>

Issue #3: The Gene Business

The science and strides made to advance what we know about human genetics has value in a market-driven society. Many of the articles in the series name companies who seek to profit on the science of the genome. Questions to consider include: Can you patent genes? Who can patent them and for what purpose? Who profits from the genome or what if only a few stand to profit? What role does the scientist/university/lab play in product-development? Should the genome be a consumable product?

Guides	Applicable Disciplines	Related <i>DNA Age</i> Articles
Consumer Genomics	All Sciences, Philosophy & Religion,	<i>Facing Life with a Lethal Gene</i>
Business of Genetics	Business, ISAT	<i>Stalking Strangers' DNA to Fill in the Family Tree</i>
Stem Cell Research		<i>Prenatal Test Puts Down Syndrome in Hard Focus</i> <i>As Breeders Test DNA, Dogs Become Guinea Pigs</i> <i>In DNA ERA, New Worries About Prejudice</i> <i>My Genome, Myself</i>

Issue #4: Identity Formation

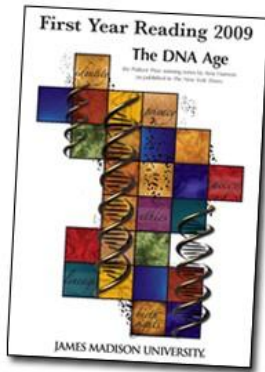
All the articles in the series touch on some element of the question “who am I?” Am I the sum total of my genetic make-up or do I have some role to play in the creation of me? As we discover more about our genes, what does this do to the concept of family? Basic issues on nature (genetically enhanced or otherwise) vs. nurture are topics for fruitful conversation. Also to consider here are issues of who were we/ him/ her? Does the present human race have access to the genes of our forebears? Could that information change what we believe about historical figures? Should it?

Guides	Applicable Disciplines	Related <i>DNA Age</i> Articles
Forensic DNA	Psychology, Sociology &	<i>Cancer Free at 33, but Weighing a Mastectomy</i>
Prenatal & Newborn Screening	Anthropology, Education, History	<i>As Breeders Test DNA, Dogs Become Guinea Pigs</i>
Deliberate Deception		<i>My Genome, Myself</i>

Issue #5: Who Gets to Know?

If you were to find out all you could about your genetic composition, who would you share that information with? Would you have any moral responsibility to share it with some, but not with others? What are the implications of you sharing your genetic information on your family members? How can sharing genetic information make us closer to some while simultaneously creating divisions between people? Should the government have your DNA? What can they do with it? What about sharing your genome on the internet?

Guides	Applicable Disciplines	Related <i>DNA Age</i> Articles
Forensic DNA	Political Science, Justice Studies,	<i>My Genome, Myself</i>
Genetic Engineering Advances or Bio-Divide?	Communication Studies, Nursing, Social Work, Health Sciences	<i>Stalking Strangers' DNA to Fill in the Family Tree</i> <i>In the DNA Era, New Worries About Prejudice</i>



Genetic Research Milestones

- 1863** Gregor Mendel, a Moravian monk, states that inherited traits are controlled by invisible elements, later called genes.
- 1865** Mendel develops the laws of heredity while studying the patterns and relationships of pea plants. The units of inheritance later become known as genes.
- 1866** Mendel publishes an article explaining the basic laws of genetic inheritance.
- 1869** British explorer and anthropologist Sir Francis Galton, a cousin of Charles Darwin, founds the modern eugenics movement, presenting evidence that intelligence runs in certain families.
- 1927** American geneticist Hermann Joe Muller discovers genes can undergo mutations. In *Buck v. Bell*, the U.S. Supreme Court upholds the constitutionality of a Virginia sterilization law. Sterilization laws were passed in 32 states between 1907 and 1937, reflecting public acceptance of using science to improve the quality of the gene pool.
- 1933** Adolph Hitler comes to power in Germany and institutes a eugenics policy that ultimately leads to the death of millions.
- 1938** German scientist Hans Spemann articulates the principles of modern cloning.
- 1940** American scientists George Beadle and Edward Tatum discover that each gene specifies the production of a specific enzyme.
- 1952** American embryologists Robert Briggs and Thomas J. King transfer genetic material from frog cells to denucleated frog eggs. Many of the eggs develop into juvenile frogs.
- 1953** James Watson and Francis Crick unveil the structure of deoxyribonucleic acid, or DNA, the material from which genes are made. English scientist Crick proclaims, "We've discovered the secret of life."
- 1962** In the first successful cloning experiment using adult cells, Oxford University zoologist John Gurdon transfers genetic material from tadpole intestinal cells into denucleated frog eggs. The result: tadpole clones.
- 1974** The Recombinant DNA Advisory Committee is established at the National Institutes of Health to develop guidelines for the safe conduct of gene research.

- 1978** U.S. geneticists J.C. DeFries and Robert Plomin report there exists a genetic component in lab animals affecting diverse behaviors like learning, sexual activity and aggression. An English woman uses in vitro fertilization to give birth to the first “test tube baby.”
- 1981** First American IVF baby, Elizabeth Jordan Carr, is born in Norfolk, Va. She is the 15th worldwide.
- 1984** In the first successful cloning experiment using adult cells, Oxford University zoologist John Gurdon transfers genetic material from tadpole intestinal cells into denucleated frog eggs. The result: tadpole clones.
- 1989** The first human gene-transfer experiment takes place at NIH, on a cancer patient.
- 1990** NIH launches the Human Genome Project, a \$3 billion, 15-year effort to map and sequence the human body's genes. Led by Watson, the Human Genome Project sets out to identify and publish the complete sequence of DNA in the human genome by 2005.
- 1993** Researchers identify genes linked to a half-dozen major illnesses, including Huntington's disease and colon cancer. Human embryos cloned by two U.S. scientists survive for several days in a Petri dish. New findings suggest homosexuality may be inherited.
- 1994** The BRCA1 and BRCA2 "breast cancer" genes are identified. Richard Herrnstein and Charles Murray draw popular attention to DNA research with their controversial book, *The Bell Curve*, which asserts IQ is largely hereditary.
- 1995** Congress bans federal funding of research on human embryonic stem cells. Congress passes Dickey-Wicker amendment, banning government funding of research that may harm a human embryo. Subsequently, it is passed annually in spending bills for the Department of Health and Human Services.
- 1996** The Health Insurance Portability and Accountability Act bans discrimination by group health insurers based upon genetic information. Scientists working on the Human Genome Project unveil a map of more than 16,000 genes in human DNA, about one-fifth of the total DNA packaged in chromosomes. English scientist Ian Wilmut and his colleagues clone first mammal ever created using adult stem cells. Six months later, on Feb. 22, 1997, Wilmut announces birth of “Dolly” the sheep.
- 1997** A furor ensues when Princeton biologist Lee Silver says that cloning might someday be used to create brainless human clones as sources of organs.
- 1998** The Clinton administration proposes legislation limiting what genetic information companies can collect from their employees. Congress' attention to genetic research increases in the wake of the cloning controversy.
- 1999** The Human Genome Project shortens its deadline for completing the genome and promises a “working draft” of the sequence by spring 2000. The Human Genome Project completes the first human chromosome ever sequenced, Chromosome 22.

- 2000** Celera and publicly funded labs in Europe and at the University of California at Berkeley publish the genome of the fruit fly -- the most complex organism sequenced to date. Scientists announce that they have completed a preliminary sequence of the human genome.
- 2001** President Bush bans research on new lines of stem cells. American fertility expert Panos Zavos announces plans to attempt cloning a human being. A New Jersey fertility doctor reveals in the British medical journal *Human Reproduction* that his pioneering infertility treatment has produced two babies with DNA from two different mothers, which he called "the first case of human germline genetic modification resulting in normal healthy children." Advanced Cell Technology of Worcester, Mass., clones human embryos for stem-cell research, but none develop past the six-cell stage. The House of Representatives passes legislation banning all forms of human cloning, but the measure stalls in the Senate because some members want to allow therapeutic cloning. President Bush says scientists may use federal funds to study human embryonic stem-cell lines created before this date, but that the government will not fund the "destruction" of more embryos.
- 2002** PPL Therapeutics, a British company, clones pigs with a key organ-rejecting gene "knocked out" of their DNA. A U.S. firm, Immerge BioTherapeutics, follows suit in January 2003. Brigitte Boisselier claims that the world's first human clone, a girl nicknamed Eve, has been born.
- 2003** The human genome is deciphered. The House once again votes to ban all forms of human cloning, and the Senate once again refuses to do so.
- 2004** Canada bans sale of human eggs and sperm and sex selection of children.
- 2005** The Food and Drug Administration requires sperm banks to test for HIV and other communicable diseases.
- 2008** Researchers discover the gene profile of glioblastoma, the deadliest brain cancer.
- 2009** England's reproductive-medicine regulatory agency says it will inform donor-conceived children at age 16 whether they're genetically related to a person they plan to be sexually intimate with.

Timelines from, CQ Researcher issues dedicated to: *Genetic Research, Human Genome Research, Reproductive Ethics*. JMU Libraries, accessed June 2009.

Controversy and Medical Technologies

Now that we have mapped the human genome, the possibilities created by affordable, accessible DNA testing is creating controversy. Explore some earlier discoveries in medical technology that generated heated debate.

Medical Breakthrough	Controversy
Dissection	In the late 15th century, Leonardo da Vinci secretly made use of human cadavers for his anatomical drawings. Dissection raised questions about where the body and soul begins and ends. Even when dissection was legalized, people did not want to donate their bodies for religious reasons. Not until WWI did people accept that bodies (which were never recovered) could be separated from the “soul”. Criminal activity, such as grave robbers, arose when medical schools began seeking cadavers. Today, dissecting cadavers is a critical component of every medical education.
Smallpox Vaccine	In 1796 Edward Jenner discovered the process of vaccination against smallpox. Controversy about effectiveness and individual rights arose. Roughly 1 in 13 children died every year of smallpox. The risk of death from the disease overcame the dissenting voices. The World Health Organization (WHO) launched a worldwide campaign to eradicate smallpox in 1967. WHO declared smallpox eradicated in 1980. There are emerging concerns that the smallpox virus will be used in bioterrorism since the population is no longer inoculated.
Anesthesia	In America, William Thomas Green Morton pioneered the surgical use of ether in 1846 and in Scotland, James Young Simpson discovered the use of chloroform. There was significant opposition in England and in Scotland. The main issue about the use of anesthesia concerned childbirth. The argument was that in Genesis 3:16 after the expulsion from the Garden of Eden — God said to the woman, "I will greatly multiply your pain in childbearing, in pain shall you bring forth children." Should we “play God” in changing that situation?
Organ Transplants	Organ transplantation started in the early 1950’s. It raised questions about human experimentation. Its misuse during World War II prompted the Declaration of Helsinki in 1964 requiring voluntary and informed consent. “Over the last five decades, surgeons have learned how to transplant virtually every vital organ in the human body. They have also branched out to transplant an array of nonvital body parts including, most recently, the hand. In the near future, face transplants, still a subject of controversy, are likely to become a reality.” ¹

Discussion Questions

1. After exploring the history of some medical breakthroughs, what surprised you? Do you see any parallels to our current debate about DNA testing, cloning, or stem cell research?
2. Medical care is a social and economical problem. What is the best way to allocate limited resources (money, expertise, organs) for the public good? How does this impact the decision about aborting a pregnancy when the fetus is diagnosed with Down Syndrome in *Prenatal Test Puts Down Syndrome in Hard Focus*?

3. A new technology takes about 20 years to enter everyday living in tangible ways. What impact do you foresee with DNA testing?

Activities

- Ask groups of four to brainstorm ways that these emerging medical technologies will change our way of life. Ask each group to share one prediction and write it on the board. Discuss the likelihood of each prediction. (Keep a list and read it ten years from now—just for fun!)

See Predictions for a new millennium by Arthur L. Caplan in *The American Journal of Bioethics* at www.bioethics.net for possible responses.

- In the article, *As Breeders Turn to DNA Tests, the Dog Becomes the Guinea Pig*, breeders are screening for desirable traits. How do you feel about government-financed research on animals? Is animal testing a necessary step in improving human health?

For more information on animal testing, see The Human Society of the United States at http://www.hsus.org/animals_in_research/animal_testing/ and the Time magazine article, *How Much Does Animal Testing Tell Us?* by Laura Blue, Tuesday, Jun. 17, 2008.

Resources

¹Altman, Lawrence K., "The Ultimate Gift of Organ Transplants," *The New York Times*, December 21, 2004.

Diethelm, A. G., "Ethical decisions in the history of organ transplantation," *Annals of Surgery*, 1990 May; 211(5): 505–520.

"Medicine's Greatest Gift," Neurosurgical Service, Massachusetts General Hospital, <http://neurosurgery.mgh.harvard.edu/History/gift.htm>

Sullivan, John T., "Surgery before anesthesia," Neurosurgical Service, Massachusetts General Hospital, <http://neurosurgery.mgh.harvard.edu/History/beforeth.htm>

Genetic Engineering Advances or a Bio-Divide?

Related DNA Age Articles

- 1: In DNA Era, New Worries About Prejudice
- 2: My Genome, Myself
- 3: Cancer Free at 33, but Weighing a Mastectomy
- 4: As Breeders Turn to DNA Tests, Dogs Become Guinea Pigs

Applicable Disciplines

- | | |
|-------------------|------|
| Political Science | WRTC |
| SMAD | ISAT |
| Justice Studies | |

Focus

With advances in genetics, some people may become discriminated against because they lack the “correct” version of a gene or they don’t have the right set of genes. Others may have more access to their genetic information than others, giving them more treatment options well in advance of the onset of symptoms. Can this create a bio-divide? Should everyone be genetically “screened” and for what? If yes, who gets access to your genetic information? Should we, as a matter of course, share our genetic information with a potential spouse, an employer, our Facebook friends?

Issues to consider

In what ways can the government ensure that individual’s genetic privacy is maintained and that society will not develop different classes based on procedures manipulating genes? How can society balance the individual’s need or right to medical information without that same information being used to discriminate against someone? Can everyone in society benefit from the power that the knowledge of the genome provides?

Discussion Questions:

1. Is there anything morally objectionable about ‘personal eugenics,’ enhancing one’s life through genetic manipulation? Would spending money on genetic enhancements be any different from spending money on cosmetic surgery? Should such options be available in the private sector as an unregulated for-profit business?
2. Should we be concerned about a bio-divide that may result in an ‘aristocracy’ of the Gen-Rich? Remember, families used to inter-marry to keep the bloodlines “pure” while simultaneously wreaking havoc on their descendants. Is this different? Why?
3. What are the long-term societal consequences of producing “genetically wealthy” and “genetically deprived” populations?

Additional Resources:

Clips from the film, *GATTACA* (available from Carrier Library, Media Resources, Videotape 6170)

Ultimate Reboot – Juan Enriquez Shares his vision for the joining of science, genetics, and robotics to create “new life.”

http://www.ted.com/index.php/talks/juan_enriquez_shares_mindboggling_new_science.html

Huxley, Aldous. *Brave New World*. Carrier Library PR6015.U9.B7

Activities/Ice Breaker:

Show students clips from the movie *GATTACA*. Have them discuss the ways in which the film depicts the way technology will alter the way we think about what “natural” conception is? Ask them if they have ever encountered prejudice based on who they are? Do they think that the government can combat such prejudice better through legislation or education?

Consumer Genomics

Related DNA Age Articles

- 1: My Genome, Myself
- 2: Stalking Strangers' DNA to Fill in the Family Tree
- 3: Cancer Free at 33 But Weighing a Mastectomy

Applicable Disciplines

- | | |
|----------|-------------------|
| Business | Health Sciences |
| ISAT | Political Science |

Some researchers say it's unclear whether people will understand the genetic risk data and what they will do with it. Is this just a bit of harmless fun? Will it improve long-term health outcomes? Or will misguided patients march to their doctors and demand expensive and unnecessary tests, harming themselves and the healthcare bottom line -- while others incorrectly see their results as destiny and adopt worse lifestyle habits? (What's one more T-bone if you are fated to die of a heart attack anyhow?)¹

What value do businesses create for customers in the emerging industry of consumer genomics?

Providing Access to Reliable Information - A Sample Report

To understand what services are provided by companies such as Navigenics, 23andMe, DNA Direct, and deCODEme, watch the first of two video clips provided by deCODEme on their website:

<http://www.decodeme.com/video-tour>

First Clip: Explains the personalized DNA testing services from the perspectives of medical professionals and researchers. They explain the value in delivering personalized DNA results to consumers. (2:40)

Second Clip: An explanation of the deCODEme report. (10:20)

Discussion Questions

1. Are we satisfying or exploiting our insatiable appetite for information about ourselves? Is it okay to pursue strangers to complete your family tree as the amateur genealogists in *Stalking Strangers' DNA to Fill the Family Tree*?
2. Will consumers understand the difference between diagnosis and risk?
3. Do you expect genetic testing to change lifestyles resulting in better health? How will your Gene Journal like Amy Harmon's in *My Genome, Myself*, impact you?

Activities

- Ask students to individually list the pros and cons to genetic testing from their personal perspectives. In groups of four, share your analyses. Identify the any group consensus.
- Christina Applegate, the star of *Samantha Who?*, decided to have a double mastectomy at age 36 after the genetic test for the BRCA gene came back positive. How do students as viewers and fans respond to this decision? Does it change how they view genetic testing? How does this situation compare to Katharine Moser's positive genetic test for Huntington's Disease in *Facing Life with a Lethal Gene*?

<http://www.cnn.com/2008/LIVING/10/14/o.christina.applegate.double.mastectomy/index.html>

"We aren't saying, 'You have no symptoms but start taking these five drugs,'" he says. "We're saying, 'This is something you should keep an eye on; here are the symptoms; here are the opportunities for early detection,'" says Navigenics cofounder, Dietrich Stephan.²

When a physician is listening to someone who has seen information on the internet, their eyes cross," says TGen president and scientific director Jeffrey Trent, who sits on Navigenics' scientific-advisory committee. "With this, [patients] will be going in with specific, selective information that's been through a process that is rigorous and scientific."²

Medical Testing Companies

Navigenics was founded in 2006 by David Agus, M.D. and Dietrich Stephan, Ph.D., with the overall goal of improving personal health. Our genetic tests were born out of scientific discoveries initially made possible by the Human Genome Project, a 13-year federal and international collaboration to identify every single human gene. Our company analyzes your DNA for risk markers that may genetically predispose you to various health conditions, including breast cancer, type 2 diabetes, colon cancer and heart attack. http://www.navigenics.com/visitor/about_us/mission/

23andMe, Inc. is the leading personal genetics company dedicated to helping individuals understand their own genetic information through DNA analysis technologies and web-based interactive tools. The company's Personal Genome Service™ enables individuals to gain deeper insights into their ancestry and inherited traits. 23andMe, Inc., was founded by Linda Avey and Anne Wojcicki in 2006, and the company is advised by a group of renowned experts in the fields of human genetics, bioinformatics and computer science. Its Series A investors include Genentech, Inc., Google Inc. (NASDAQ: GOOG) and New Enterprise Associates. More information is available at <https://www.23andme.com>.

DNA Direct was founded in 2003 to address the growing need for genetic expertise and guidance across the healthcare continuum. Genetic technology is rapidly advancing and new associations between common genes and disease are being discovered every day. With more than 1600 genetic tests available today, the impact of genetics has never been greater and is becoming an integral part of medicine and patient care. http://www.dnadirect.com/web/about_dna_direct/about-dna-direct

deCODE genetics has an unrivaled track record in gene discovery. In the past year alone, our scientists have identified major inherited risk factors for diseases including type-2 diabetes, heart attack, breast cancer, prostate cancer, glaucoma and restless leg syndrome. These breakthroughs are based upon our unique resources and expertise. deCODE Genetics' laboratories are among the largest in the world and use state-of-the-art technology in every division of the company. All our results are vetted by our experts and supported by publications in peer-reviewed, internationally renowned scientific journals. <http://www.decode.com/>

Resources

¹Goslin, Anna, Genome Scans Go Deep Into Your DNA, *Los Angeles Times*, April 14, 2008

²Bower, Amanda, Are There Holes in My Genes? *Fast Company*, December 19, 2007

Deliberate Deception?

Related *DNA Age* Articles

- 1: My Genome, Myself
- 2: Facing Life with a Lethal Gene
- 3: Cancer Free at 33, but Weighing a Mastectomy

Applicable Disciplines

- | | |
|-------------------|-----------------|
| Political Science | Business |
| Math/Statistics | Health Sciences |
| Psychology | |

Focus

The explosion of statistically tentative genetic information is a goldmine to those who prey on the general public's poor understanding of science and statistics.

Issues to consider

How can society balance two competing demands: the right of an entrepreneur to sell a product or service to a willing market, and the ethical duty to prevent consumer fraud? Should the government police direct-to-consumer genetic testing, or is the onus on the consumers to properly educate themselves?

The Food & Drug Administration (FDA) has a history of writing "regulations" written by the companies they supposedly regulate. Is there any reason, then, to believe that government agencies would act as effective watchdogs and provide regulatory oversight over public health and safety?

The U.S. is the only Western/industrialized country that permits direct-to-consumer marketing of prescription drugs. Why should genetic 'tests' be any different or raise ethical concerns? Everything else is being sold to American consumers in a lax, caveat emptor environment, so why should consumers be especially concerned about 'genetic enhancement products'?

Viewpoint/Discussion Point

Government Role	The FDA already has authority to regulate drugs and medical testing laboratories. The possibility of harm and wasted money is reason enough to include specific regulations for direct-to-consumer genetic testing.	The test itself cannot harm the consumer, unlike a drug; the companies are simply providing information. What the consumer does with that information is a personal choice.
Outcome for Consumer	Consumer makes healthy lifestyle changes (e.g. eating better, exercising, quitting smoking)	Consumer duped into buying expensive supplements from company; makes drastic life choices (e.g. refuses to have children so as not to pass on "bad genes"); suffers anxiety based on inconclusive or spurious results
Impact on Health Care	Consumer increases preventative care measures (makes basic healthy lifestyle changes and decreases risk of several diseases that are not dependent on genetic background)	Consumer demands increased medical surveillance, unnecessary tests and medications, raising health care costs and insurance premiums

Additional Resources :

NUTRIGENETIC TESTING: Tests Purchased from Four Web Sites Mislead Consumers, United States Government Accountability Office, July 2006 (<http://www.gao.gov/new.items/d06977t.pdf>)

Innumeracy: Mathematical Illiteracy and its Consequences by John Allen Paulos (Hill and Wang, 2001)

[At-Home Genetic Tests: A Healthy Dose of Skepticism May Be the Best Prescription](http://www.ftc.gov/bcp/edu/pubs/consumer/health/hea02.shtm) (Pamphlet from Federal Trade Commission) <http://www.ftc.gov/bcp/edu/pubs/consumer/health/hea02.shtm>

Illusive Gold Standard in Genetic Ancestry Testing, Science, 3 July 2009, Vol. 325, 38-39.

Activities/Ice Breaker:

1. Ask the class the following questions:

a. You read about a recent study that suggests that drinking tap water will increase your lifetime chances of toenail cancer by 100%. Would you stop drinking tap water and switch to bottled water?

b. You read about a recent study that suggests that drinking tap water will increase your lifetime chances of toenail cancer from 0.5% to 1%. Would you switch to bottled water?

c. You read about a recent study that suggests that drinking tap water will increase your lifetime chances of toenail cancer from 20% to 40%. Would you switch to bottled water?

(Of course, all three questions have a statistical increase of 100%. How does the psychological impact of each question differ? How many students assumed that the 1st question meant “a 100% chance of toenail cancer”?)

Forensic Use of DNA

Related *DNA Age* Articles

- 1: My Genome, Myself: Seeking Clues in DNA
- 2: Stalking Strangers' DNA to Fill in the Family Tree
- 3: In DNA Era, New Worries about Prejudice

Applicable Disciplines

- | | |
|------------------|-----------------------|
| Criminal Justice | Political Science |
| Psychology | Communication Studies |
| Sociology | SMAD |

Focus

DNA evidence has become a vital tool for both prosecutors and defense lawyers and is well-known to the general public through TV shows such as CSI and NCIS. But the public's perception of DNA evidence does not always match the reality, and there are thorny legal issues regarding the use of DNA in criminal trials.

Issues to consider:

1. There is some debate in the judicial community over whether a "CSI effect" exists: jurors who watch forensics shows on television demanding unrealistic levels of accuracy and availability of forensic evidence in order to convict a defendant. How does the use of DNA evidence on the TV shows differ from that in real life, and how can prosecution lawyers and judges counteract unrealistic expectations?
2. Two Supreme Court cases from this year's docket deal with the use of genetic evidence in trials. In *Melendez-Diaz v. Massachusetts*, the Court decided that a defendant has the right to cross-examine the crime lab technician who analyzed the evidence in his/her case (previously, most states had allowed the lab to submit a certificate with the results, considering this as evidence rather than testimony). In *District Attorney's Office for the Third Judicial District et al. v. Osborne*, the Court decided that a convicted defendant does not have the right to ask that new analysis techniques (unavailable at the time of the trial) be applied to forensic evidence used in the initial conviction. How might these decisions affect the behavior of police, crime lab technicians, prosecution lawyers, and defense lawyers?
3. Behavioral geneticists are starting to uncover genes that affect personality traits of interest to the criminal justice system: potential for violent behavior, susceptibility to addiction, and impulsivity, among others. How could this information be used by trial lawyers? Where is the line between personal responsibility and genetic predisposition? Is there a danger of being branded a "pre-criminal" if you have these genes, but have not yet committed any crimes?

Additional Resources :

["The CSI Effect: Popular Fiction About Forensic Science Affects Public Expectations About Real Forensic Science."](#)
Jurimetrics, Spring 2007: 357.

"The CSI Effect: Fact or Fiction" Yale Law Journal Pocket Part (<http://www.thepocketpart.org/2006/02/thomas.html>)

Supreme Court decision in *Melendez-Diaz v. Massachusetts* issued on 6/25/09

(<http://www.supremecourtus.gov/opinions/08pdf/07-591.pdf>)

(http://www.scotuswiki.com/index.php?title=Melendez-Diaz_v._Massachusetts)

Supreme Court decision in *District Attorney's Office for the Third Judicial District et al. v. Osborne* issued on 6/18/09

(<http://www.supremecourtus.gov/opinions/08pdf/08-6.pdf>)

(http://www.scotuswiki.com/index.php?title=District_Atorney%27s_Office_for_the_Third_Judicial_District%2C_et_al._v._Osborne)

“Genes on Trial” Part of a PBS series “Our Genes, Our Choices” that aired in January 2003.

(http://www.pbs.org/inthebalance/archives/ourgenes/genes_on_trial/genes_index.html), Available on videotape, Carrier Library Media Resources tape 8267.

Activities/Ice Breaker:

The PBS program “Genes on Trial” has several polls, scenarios, and other resources that could be used to get students talking. For example,

“Imagine that a scientist from the state university asks you and your family to participate in a study on a particular gene variant associated with alcoholism. The project focuses on your ethnic group, the Tracy Islanders, who have a higher incidence of alcoholism, as well as a higher incidence of the gene variant, than the general population. You will not be informed whether you have the gene variant, but your participation in the study might help scientists develop drugs to help individuals control their addiction to alcohol. You have a family history of alcoholism, and you are concerned that your twenty-one-year-old son may be susceptible to the condition as well. Do you agree to participate in the study?”

Now imagine that, with your participation, the study concludes that Tracy Islanders with the particular gene variant have a ten percent chance of becoming alcoholics, whereas Tracy Islanders without the gene variant have only a five percent chance. Although the scientists are careful to note that the gene variant exists in the general population and is not the cause of alcoholism, the sound-bite reported by the media is that Tracy Islanders are hardwired to become alcoholics.

That same day, your son gets drunk at a bar and pushes an off-duty police officer through a window, killing him. Your son is charged with murder, and his lawyer wants to use his genetic predisposition toward alcoholism as a defense. Some members of your family and community are concerned that this approach will only further stigmatize Tracy Islanders as alcoholics. How do you advise your son and his lawyer?”

Prenatal & Newborn Screening

Related *DNA Age* Articles

- 1: Prenatal Tests Puts Down Syndrome in Hard Focus
- 2: As Breeders Turn to DNA Tests Dogs Become Guinea Pigs
- 3: After a DNA Diagnosis: "Hello 16p11.2 Are You Just Like Me?"

Applicable Disciplines

- 1: Philosophy & Religion
- 2: Political Science
- 3: Justice Studies
- 4: Nursing
- 5: Social Work
- 6: Health Sciences
- 7: Communication Studies

"Nearly 4 million U.S. newborns undergo genetic screening each year. In the past, such screening was limited to diseases for which effective treatment was available. Now most mandatory programs also screen for conditions with no effective treatment."¹

What are some of the ethical issues to consider when developing public policy on the issue?

Moral Dilemma

"In the United States today, almost all infants are screened at birth for between thirty and fifty genetic disorders, depending on the screening program of the state in which they are born. Of the approximately four million babies screened each year, about 5,000 are identified as having serious heritable disorders, most of which are, in varying degrees, amenable to treatment."²

Debate the traditional (last 40 years) and emerging views of newborn screening.

View	Traditional	Emerging
	The availability of a reliable test is justified if it provides a direct medical benefit to those who test positive.	Routine screening is justified for biomedical research.
Moral Focus	What is good for the infant	What is good for the family and society with an indirect benefit to the infant
Outcome	Successful treatment of disease	Discoveries of treatments for rare, poorly understood or currently untreatable disease

Ethical Issues

1. If screening is used for biomedical research, do researchers keep the information confidential or share it with the parents?
2. Do parents have the right to refuse screening?
3. If the number of children with a genetic disorder like Down Syndrome declines, do we as a community need to continue to provide costly support services?

Policy/Legal Considerations

1. Should states require mandatory newborn screening?
2. Should states offer voluntary screening for research purposes?

Activities

- First-time parents are trying to decide whether to test their unborn child for Down Syndrome, as discussed in the article, *Prenatal Test for Down Syndrome in Hard Focus*. Invite four students to be the voices of the unborn child, parents, and doctor. The audience can play the role of the bioethics researchers who are looking out for the common good. What questions and concerns are raised by each participant in this situation?
- In groups of four, share any personal experiences in which you have been impacted by children with birth defects or disabilities. If these health issues could be identified early through genetic screening and treated, is it worth it?

Resources

¹ The President's Council on Bioethics, www.bioethics.gov.

² "'Genetic Exceptionalism' in Medicine: Clarifying Differences between Genetic and Nongenic Tests," *Annals of Internal Medicine* 138 (2003): 571-575.

³ *The Changing Moral Focus of Newborn Screening*, An Ethical Analysis by the President's Council on Bioethics, December 2008.

March of Dimes at <http://www.marchofdimes.com/home.asp>

Scientific Literacy and Decision Making

Related *DNA Age* Articles

- 1: Cancer Free at Age 33, but Weighing a Mastectomy
- 2: Prenatal Test Puts Down Syndrome in Hard Focus
- 3: My Genome, Myself: Seeking Clues in DNA

Applicable Disciplines

- | | |
|-----------------|----------------|
| Biology | Health Science |
| Math/Statistics | Social Work |
| Education | Sciences |

Focus

The explosion of genomic information available to the general public (about themselves and others) should help people make better-informed decisions about their health, social concerns, and certain political issues. However, many citizens do not have the level of scientific literacy necessary to fully understand the implications of this information, and may make poor decisions based on faulty understanding.

Issue to consider

How can we ensure that people truly understand the benefits and limitations of genomic information?

Discussion Questions:

1. What are the roots of low scientific literacy among Americans?
2. Most adults are finished with their formal schooling, and thus traditional methods of instruction are not feasible. Should there be a general push to increase genetic understanding for the public as a whole, or should doctors/scientists instruct citizens on a case-by-case basis (i.e. during a medical appointment; when individual political issues come to the public's attention; before undergoing certain tests or procedures)?
3. Most medical tests or research protocols call for informed consent from the participant. However, research is beginning to show that some participants have such poor scientific literacy that they do not understand the informed consent information, and thus do not fully understand potential risks and the true likelihood of benefits. How can this issue be remedied?
4. How can doctors and research scientists better explain risks and benefits to their patients and the public?
5. What are the differences between educating people about the scientific basis of an issue (Ms. Linder's lifetime risk of breast cancer, Ms. Moser's anticipated symptoms and onset of Huntington's disease) and counseling people about the emotional impacts (Ms. Linder's decision to remove her breasts at 33, Ms. Moser's knowledge of inevitable neurological decline, life with a Down's syndrome child)?
6. Are there certain decisions that we should not allow people to make until they can demonstrate that they truly understand the issues and information involved? Is this overly paternalistic? Is it even feasible? Does it make a difference if the bad decision punishes only the individual versus having costs for society?

Additional Resources :

“Helping Doctors and Patients Make Sense of Health Statistics,” *Psychological Science in the Public Interest* 8(2008): 53-96

Activities/Ice Breaker:

1. You read about a recent study that suggests that drinking tap water will increase your lifetime chances of toenail cancer by 100%.

Would you stop drinking tap water and switch to bottled water?

You read about a recent study that suggests that drinking tap water will increase your lifetime chances of toenail cancer from 0.5% to 1%. Would you switch to bottled water?

You read about a recent study that suggests that drinking tap water will increase your lifetime chances of toenail cancer from 20% to 40%. Would you switch to bottled water?

Of course, all three questions have a statistical increase of 100%. How does the psychological impact of each question differ? How many students assumed that the 1st question meant “a 100% chance of toenail cancer”?

2. A doctor tells a couple that their genetic makeup means that they've got one in four chances of having a child with an inherited illness. Does this mean that if their first three children are healthy, the fourth will have the illness?”

“Does this mean that each of the couple's children will have the same risk of suffering from the illness?”

“Does this mean that if they have only three children, none will have the illness?”

(From National Science Foundation’s “Public Understanding of Science” Survey. Roughly 1 out of 5 respondents missed each question. http://www.ropercenter.uconn.edu/data_access/data/datasets/nsf.html)

3. Activities 4 and 5 from “Human Genetic Variation” written by the NIH and BSCS have well-designed role-playing materials dealing with the same type of early double-mastectomy decision in one of the assigned articles. (http://science-education.nih.gov/supplements/nih1/Genetic/guide/guide_manual_toc.htm) A possible extension to this type of activity is to ask what types of information someone in that situation (or a similar one) would need to know to make an informed decision, and what problems that person would face if they did not fully understand the science involved.
4. Display advertisements for medicines, medical tests, medical warnings, etc. and ask students to identify possible misunderstandings arising from the item. (The *Psych. Sci. Pub. Int.* article references in “Additional Resources” has some good examples.)

Therapeutic Cloning & Stem Cell Research

Related DNA Age Articles

- 1: Facing Life with a Lethal Gene
- 2: After DNA Diagnosis: 'Hello, 16p11.2. Are You Just Like Me?'
- 3: Prenatal Test Puts Down Syndrome in Hard Focus

Applicable Disciplines

- | | | |
|-----------------|-----------------------|------|
| Bioethics | Political Science | |
| Biology | Philosophy & Religion | |
| Justice Studies | Sciences | ISAT |

Focus

Therapeutic cloning is the use of stem cells (blank cells able to differentiate into any type of cell) to repair damaged genetic material. Stem cells can be derived from embryos, but result in the destruction of the embryos. Is this science advancing or murder?

Viewpoint/Discussion Point	Traditional /Historical	Emerging
Role of Government	Individuals have a right to privacy when it comes to medical procedures (<i>Roe v. Wade</i>).	The federal government should not fund the destruction of human embryos (Pres. Bush, August 2001).
Role of Science	Scientists conducting research do not worry about the effects of their discoveries.	Scientists need to consider the impact their work will have on society.

Ethical Issues to consider

Do the risks of therapeutic cloning outweigh the potential benefits? Can the destruction of human embryos to harvest stem cells be equated with killing unborn children?

Implications for Society

1. If stem-cell research is successful, many genetic disorders could be eradicated, not only in future generations, but also in living individuals. Scientists believe that stem cell research might hold the cures for Alzheimer's, diabetes, heart disease, stroke, and many types of cancer. Does saving the lives of the already born trump the "rights" of embryos.
2. Is it worth conducting research that will lead to the destruction of human embryos in the lab if such research may provide relief for tens of thousands of humans?

Additional Resources:

Human Genome Project Cloning Fact Sheet http://www.ornl.gov/sci/techresources/Human_Genome/elsi/cloning.shtml

AAAS Policy Brief on Human Cloning <http://www.aaas.org/spp/cstc/briefs/cloning/index.shtml>

"Stem-Cell Research Follow-up: Obama Lifts Stem Cell Funding Ban." [Issues & Controversies On File](#) 9 Mar. 2009.

Activity:

In March 2009, President Obama lifted the ban on stem cell research for federally funded labs (in 2001 then President Bush limited stem-cell research to stem cell lines in existence created in private labs). With this lift the President left open the question as to where the stem cells could legally come from in order to receive federal research funding. Under the Bush ban, only embryos created by couples seeking to have children were eligible for funding research. This raises the question, can labs (with or without federal funding) create embryos with the sole purpose of harvesting them for stem-cell research? Should the federal government fund research of this type? What sort of ethical questions does this type of question raise? Have the student identify the thorny questions, without having them come to conclusions as to what "the answer" or "a solution" might be.

Facilitator's Discussion Template*

DNA Age Articles Related to this Topic

1:
2:
3:

Academic Disciplines that consider this issue

1:
2:
3:

Focus

Broad Description of Topic – see the topics addressed in other guides or create your own based on the reading(s).

Dilemma or Issue to consider

Think of this as the “debate statement” take an issue or stance on an issue that is under the umbrella of the broad topic above and then consider all sides of the issue

Viewpoint/Discussion Point	Viewpoint One	Viewpoint Two
Issue One		
Issue Two		
Issue Three		

Ethical Issues to consider?

Implications for Society?

Additional Resources :

Activities/Ice Breaker:

**For use for facilitators who wish to create their own topic related to the readings, but want some structure from which to work.*

Structured Conversation Starters

Line-Up, Think Pair Share, and Appointment Clock are all activities designed to get students up and speaking to each other and to the facilitator about an issue or text. Thanks to the Center for Faculty Innovation (CFI) for sharing these activity ideas. If you plan on using activities like this, you might consider taking your own supply of pencils and paper as the student may not have these items with them.

Line – Up

Purposes:

- To change the context for learning
- To provide an opportunity for the learners to get to know each other
- To have learners practice or review academic content
- To engage in dialogue with someone with a different perspective

Directions:

- The facilitator tells the learners to line up according to a particular pattern (opinion, height, birthday, etc.)
- If lining up by opinions, the facilitator poses a well-stated question with possible responses that can be put into a continuum (the line)
- The facilitator clusters contiguous learners into small groups to answer questions, solve a problem, review academic content, discuss the question that created the line-up, etc.

Tips/Suggestions/Modifications:

- You may structure the line-up so learners communicate non-verbally to form the line (use of birthdays for example)
- “Fold the line” to make small groups or pairs of learners
- Line-up can be used in conjunction with some other activity that requires small groups or pairs.

Appointment Clock

Purpose:

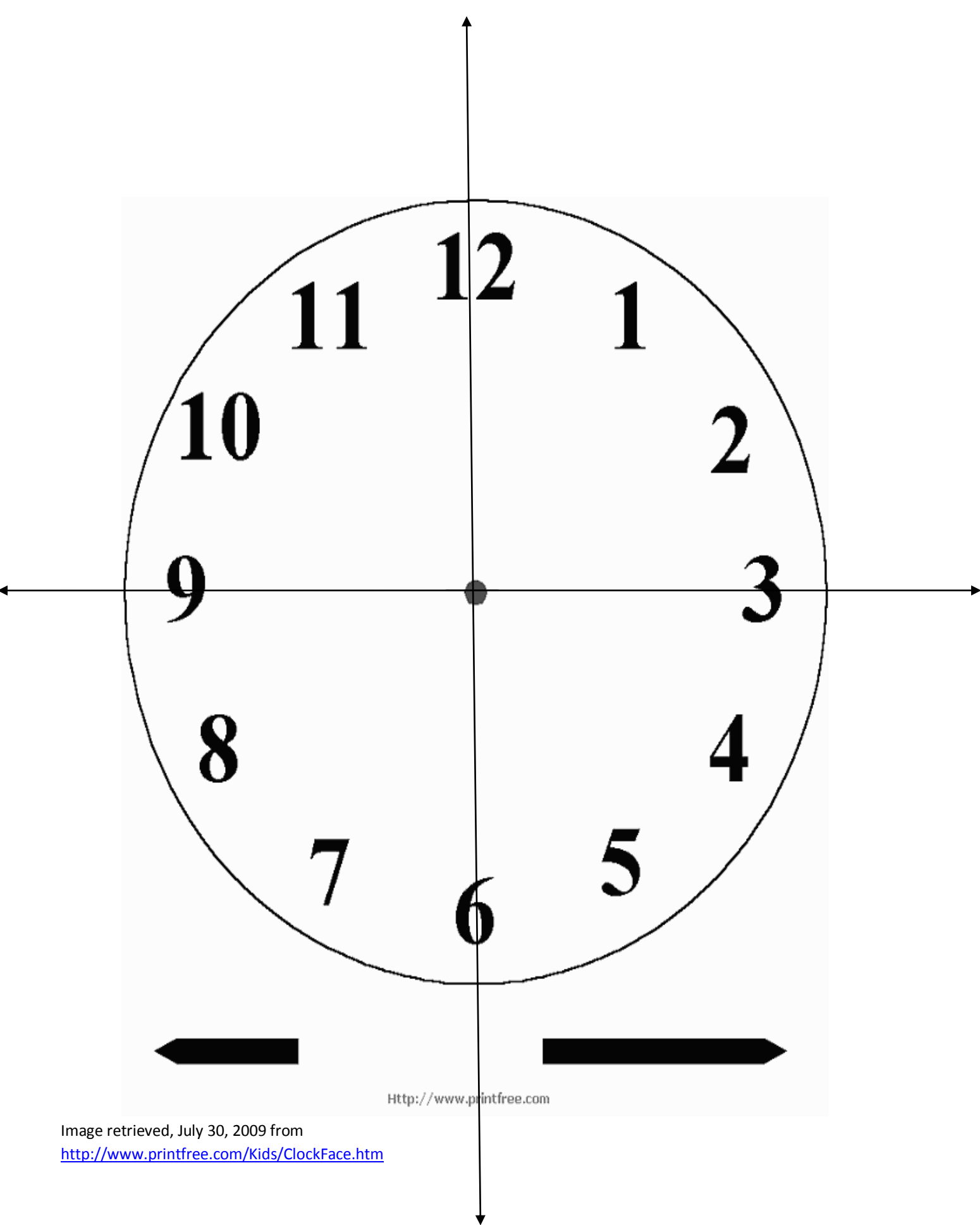
- To structure “times” when learners can partner with someone new to discuss a question, prompt or activity

Directions:

- Facilitator tells the learners to draw the face of a clock (or use one on the following page)
- Learners are asked to find someone else in the room and schedule an “appointment” for 12, 3, 6, 9 o’clock
- Learners introduce themselves to another person and ask “Are you free at _____ for an appointment?”
- If the other person is available, each person writes the other person’s name next to the time that they have mutually available
- If the other person is not available, politely decline the invitation and find someone who can make an appointment at that time
- When all four time slots are scheduled, the learners return to their seats.
- During the course of the discussion, the facilitator stops, poses a discussion question and tells the learners to find their ____ appointment
- Learners find their appointment and discuss the prompt/discussion question

Tips/Suggestions/Modifications:

- Be sure to stress the importance of writing down the names of scheduled appointments. Learners have been known to forget to do so which can lead to double-scheduled appointments and chaos
- As the scheduling progresses, clocks will get filled. Some people will not be able to find others with free appointments when they need them. In this case, ask existing partnerships to take in a third person for a particular appointment time.



[Http://www.printfree.com](http://www.printfree.com)

Image retrieved, July 30, 2009 from
<http://www.printfree.com/Kids/ClockFace.htm>

Think/Pair/Share

Purposes:

- To provide learners with time to process information
- To allow connections to be made between what is said and what is understood
- To get different perspectives on a issue or problem

Directions:

- The facilitator poses a question to be answered
- The learners are directed to think silently – give them a time limit
- The facilitator tells the learner to turn to their neighbor (left/right/behind)
- The learners share their thoughts
- The facilitator asks learners to share their partners answers or their collective points

Tips/Suggestions/Modifications:

- Be sure to wait 3-10 seconds for learners to have time to think. This is especially important for reflective learners
- The amount of time for sharing depends on the complexity of the question posed
- Having regular “sharing partners” reduces the time to reform pairs (for use in multiple question settings)
- Learners can be asked to jot down their ideas before pairing and sharing
- The facilitator can call for volunteers to speak to the collective group, share their own answers
- This is an effective technique for breaking up a lecture and actively involving students in processing the information being covered