Title: Teaching a Lesson in Bioethics in a Biotechnology Class

Kathy Savage, Chemistry Teacher
Oviedo High School

“One can be no better a teacher than one is a learner at any point in one’s life.” Paul Saltman

Abstract: Students are becoming more and more aware of the increasing number of bioethical issues that face our nation and the world every day. Topics such as whether cloning, stem-cell research, and genetically modified organisms should be allowed further advancement in research or in practice will, no doubt, come up at some point in the teaching of a biotechnology course. As students start to understand the science as well as the techniques being used in these fields, we also need to prepare them to understand the ethical dilemma faced by researchers and politicians as they struggle to agree on the ethical standards that societies must obey. This lesson is a first year attempt to teach a brief history of ethics and promote civil discussion of some ethical issues among first year biotechnology students. Students will have a chance to reflect on their own preconceived notions of what is ethical as well as to share and discuss their ideas with their classmates.

Rationale: As my Biotechnology students and I discussed the first PowerPoint of the year, “What is Biotechnology and what can it be used for?”, questions immediately arose from the students regarding certain ethical issues. The students were animated and very anxious to share their opinions on topics such as cloning and stem cell research. I recalled the presentation by Ray Moseley, Ph.D. and his comment that there was a “difference between rational opinions and rationalizing opinions”. I quickly realized that my students not only needed some introductory education to ethics, but would welcome it.

Goals: The National Institute of Health (NIH) and the National Science Teachers Association (NSTA) states four possible goals for teaching bioethics in a classroom; 1) to advance science understanding, 2) to prepare students to make informed, thoughtful choices, 3) to enhance respectful dialogue among those with diverse views, and 4) to cultivate critical-reasoning skills. These goals can be viewed in the webinar located on the NSTA’s Learning Center website. I believe that all of these goals must be kept in mind as the main objectives for teaching ethics.

Action Research Intervention: The lesson will involve two modules. The first module is a lecture/discussion based on a PowerPoint (attached). The PowerPoint will include a brief overview of some of the more renowned historical cases of ethical misconduct and the evolution of our current national policies on human research. The lesson also includes a discussion of vocabulary and some ground rules for discussing ethical issue in class. The second module involves breaking the students into groups and allowing them to discuss two separate biotechnical ethical questions. The first question is whether or not a country or nation should financially benefit from bacteria that can be found only in within their boundaries. The specific example used is that of an enzyme extracted from an extremophile in Lake Nakuru, Kenya in the
1980’s. The enzyme was sold to Genencor International, a company with close ties to Proctor & Gamble. The students will read, “Who Benefits from African Research?” by Christine Gichure. (This article can be read online at the website listed in Literature Cited below). The second question is whether or not individuals should financially benefit from medical research that used their DNA or cells. The specific example will be that of HeLa cells which were extracted from a tumor in a woman by the name of Henrietta Lacks in 1951. The students will read Rupert Cornwells’ article “The Incredible Story of the Most Important Woman in the History of Modern Medicine.” (This article can also be read at the website listed in the Literature Cited below.) The students will write a brief paragraph describing their opinions before their discussion and then again after their discussions. The entire two modules should be completed within a two week time period.

**Day One:** The first day students will be given a pretest and survey. The class can discuss the terms/values in the value exercise to determine which words/values have a place in a discussion regarding ethics.

**Days Two and Three:** The second and third day will be spent on a PowerPoint defining terms, protocol on discussion vs. debate, and a discussion of the Institutional Review Board’s formation and consensus regarding human subjects in research. The PowerPoint will not be presented solely as a lecture, but rather as a talking point for interactive class discussion.

**Days Four and Five:** Students will answer the following question in a paragraph before the lesson begins; “If you found a bacteria, that was not known to exist before, in the Little Econlockhatchee River and found a valuable industrial use for it, do you think that the state of Florida should benefit financially from your research? Why or why not?”. The students will then read the article “Who Benefits from African Research” from the website. After reading the article the students will be assigned to groups where they will be allowed to discuss their views. Once each group has discussed their views we will reconvene as a class and wrap up the discussion. At the conclusion the students will write a paragraph describing whether or not they would change their original answer to the “Little Econ” question and what, if anything, made them change their mind.

**Days Six and Seven:** Students will answer the following question in a paragraph before the lesson begins; “Assume that while you were under the care of a physician for a type of skin cancer a doctor, without your knowledge, took a sample of your cancer cells. Research using these cells resulted in the discovery of a cure for this specific type of skin cancer. Do you feel you should be financially compensated for the use of your cells? Why or why not?”. The students will then read the article “The Incredible Story of the Most Important Woman in the History of Modern Medicine” from the website listed. After reading the article the students will be assigned to groups where they will be allowed to discuss their views. Once each group has discussed their views we will reconvene as a class and wrap up the discussion. At the conclusion the students will write a paragraph describing whether or not they would change their original answer to the “Skin Cancer” question and what, if anything, made them change their mind.

**Day Eight:** Review & Conclusions

**Day Nine:** Post Survey and Post-test
**Connections to Bench to Bedside Summer Institute:** I found Dr. Moseley’s presentation on Bioethics to be extremely thought-provoking. Before his presentation, I truly thought I had a good handle on what the subject of ethics involved. I quickly found out otherwise. As we listened to caring and thoughtful presenters like Dr. David Weinstein who uses Maltese dogs in his research to find a cure for Glycogen Storage Disease to Dr. Barry Byrne discuss the “Critical role of Preclinical Models in Molecular Medicine” I realized that ethics was not something that could be avoided. People who think “all” animal testing is wrong don’t realize how much their own quality of life is a result of animal testing. Nor do they realize the sacrifice that another type of animal, humans, have made for the benefit of us all. Whether in clinical trials or in the long hours of education and research, the cumulative effect of individual human sacrifices is immeasurable.

**Data Collection and Analysis:** There will be three types of data collected from this research. The first will be the pre- and post-test of ten multiple choice questions. This is a criterion-referenced test rather than an opinion test. This will be the easiest to evaluate. I will use the mean, median, and standard deviation to evaluate the learning gains made by the students as a class.

The second piece of data collected will be the pre- and post-survey. This will be used to see how students view the term “ethics” with respect to other nearly synonymous terms and if their opinions changed over the course of the lesson. For this survey the median scores of a 4-point Likert scale test will be used to determine shifts in attitude.

The last piece of data collected will be the reflective paragraphs written by the students before and after their specific ethical situation group discussions. These writings will allow me to be reflective in my own analysis of the lesson and perhaps notice any gaps in what I should be teaching.

**Literature Cited:**


"Dealing with Charged Topics in the Classroom," audio [podcast] from a fall 2005 Berkeley Topics on Teaching event. Professors Mark Brilliant, History, Kristin Luker, Sociology, and Rich Muller, Physics discuss their approach to teaching and dealing with what can be difficult topics.

<http://www.ethicalbusiness.nd.edu/pdf/african%20research%20benefits.pdf>


**Budget and Budget Justification:** There are no costs associated with this lesson other than possibly printing off class sets of the situational examples or other articles for students to read. The pre- and post-tests as well as the surveys will be done on the computers in the computer lab through Blackboard.

**Permissions:** I should not need permission from parents or students for this research, however, I will make my Assistant Principal and Principal aware of my research plans.
Pre–Survey / Post-Survey

Identify each word or phrase below as being highly relevant to an ethical discussion on whether or not we should allow human cloning or not at all relevant to the discussion. Put an “x” in the box you feel most closely identifies with your assessment.

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<thead>
<tr>
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<th>1 – highly relevant</th>
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<td>8.</td>
<td>Fairness</td>
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<td>10.</td>
<td>Purpose/Intent</td>
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Bioethics

Pre-test/Post-test

1. Which of the following is not a characteristic of an “ethical” value?
   a. Humane
   b. Legal
   c. Good
   d. Right

2. Which of the following is not one of the three vulnerable research subjects as established by the “Common Rule”?
   a. Pregnant Women
   b. Prisoners
   c. Children
   d. The Elderly

3. The National Research Act of 1974 was passed as a result from the publicity of the
   a. Nazi Medical War Crimes
   b. Willowbrook Hepatitis Studies
   c. Tuskegee Syphilis Experiments
   d. San Antonio Contraceptive Studies

4. Which of the following was not one of the three key points added to the Helsinki Declaration?
   a. Established specific requirements for informed consent
b. The interest of the subject has higher priority than society
c. Every subject should get the best known treatment
d. Independent reviews of all human subject research are required

5. Thalidomide is a drug that was used for/as
   a. Treating syphilis
   b. Treating morning sickness
   c. Treating baldness
   d. Birth Control

6. The Nuremberg Code or the International Code of Research Ethics includes all of the following requirements for experiments except:
   a. All drugs used for experimentation must have FDA approval
   b. Voluntary and informed consent
   c. Experiments must be scientifically necessary
   d. The right to withdraw without penalty

7. Which of the following is not one of the four bioethical principals?
   a. Autonomy
   b. Non-maleficence
   c. Integrity
   d. Justice

8. HeLa cells are a specific cell line that
   a. Have been growing in labs since 1951 and are considered immortal
   b. Were used in the Nazi Medical War Crimes in 1936
   c. Are grown from rat ovaries and used for fertility research
   d. Were used to “treat” syphilis patients in 1940

9. “I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.” is part of
   a. The Hippocratic Oath
   b. The Common Rule
   c. The Belmont Report
   d. The Helsinski Declaration

10. Which of the following an incorrect way to frame an ethical question?
    a. Is it wrong to murder a two month old fetus?
    b. Should a three month old fetus be considered a child?
    c. At what stage in a pregnancy should abortions no longer be allowed?
    d. Does a three month old fetus have a developed nervous system?
Bioethics
Teaching Chemistry
• Importance of general knowledge for an educated public.

Biotechnology
• Controversial Issues such as:
  • Cloning
  • Stem Cell Research
  • Genetically Modified Organisms, etc.
- Emotional Debates regarding evolution, climate change, etc.
- Presentation by Ray Moseley, Ph.D. during CPET “difference between rational opinions and rationalizing opinions”
- Lack of general science knowledge among general population doesn’t exclude public from strong “opinions”.

Why Bioethics?
1. To advance science understanding
2. To prepare students to make thoughtful, informed choices
3. To enhance dialogue among those with diverse views
4. To cultivate critical-reasoning skills
1 – highly relevant  
2 – somewhat relevant  
3 – slightly relevant  
4 – not at all relevant

1. Morality
2. Theistic Values
3. Personal Opinion
4. Legal Precedence
5. Societal Tradition
6. Democratic Majority
7. Logic
8. Fairness
9. Facts
10. Purpose/Intent
1. Lecture
2. Group Discussion using case studies
3. Class Discussion

Three Modules
1. Pre-test & Survey
2 & 3. PowerPoint
8 & 9. Review & Conclusions
10. Post-Test

Two Weeks
1. What is Bioethics?
2. History of Bioethics?
3. The Belmont Report
4. Rules for discussing Bioethical issues
5. Prominent Ethical Codes
One should not identify ethics with religion. Most religions, of course, advocate high ethical standards. Yet if ethics were confined to religion, then ethics would apply only to religious people. But ethics applies as much to the behavior of the atheist as to that of the saint.

What is not “Ethics”??
Being ethical is also not the same as following the law. The law often incorporates ethical standards to which most citizens subscribe. Our own pre-Civil War slavery laws and the old apartheid laws of present-day South Africa are grotesquely obvious examples of laws that deviate from what is ethical.

What is not “Ethics”? 
Finally, being ethical is not the same as doing "whatever society accepts." In any society, most people accept standards that are, in fact, ethical. But standards of behavior in society can deviate from what is ethical. An entire society can become ethically corrupt. Nazi Germany is a good example of a morally corrupt society.
**Ethics** is a set of well-founded standards of **right and wrong** that prescribe what humans ought to do, usually in terms of rights, obligations, benefits to society, fairness, or specific virtues. **Ethics** is the study and development of one's ethical standards.
1. That are held in common by virtually all human beings.
2. That have had to be worked out by all human societies.

1. Tuskegee Syphilis Experiment (1932-72)
2. Nazi Medical War Crimes (1935-45)
4. Thalidomide Experience (1962)
5. Jewish Chronic Disease Hospital Study (1963)
6. Willowbrook Hepatitis Study (1963-66)
7. San Antonio Contraceptive Study (1970’s)
• Conducted by the United States Public Health Service
• 400 Black Males with syphilis
• 200 Black Males without syphilis as controls
• Natural History of untreated syphilis
• Men were recruited without informed consent & actually were deliberately “misinformed” in many cases
• Penicillin was found to be an effective cure in the 1940’s and was widely available by 1951.

Tuskegee Syphilis Experiment
1932-1972
To determine whether healthy people rejected cancer at a faster rate than those who were already debilitated

Injected liver cancer cells into 22 senile patients who were hospitalized with various chronic debilitating diseases.

Patients nor their families were told so as “not to frighten them” unnecessarily.

Researchers “defended” their views by with the assertion that they had good cause to predict the cancer cells would be rejected.

Jewish Chronic Disease 1963
• Tranquilizer, pain-killer, etc. eased effects of morning-sickness in pregnant women.
• Responsible for over 12,000 babies in 46 countries born with phocomelia
• Not known that drugs could cross placental barriers and affect fetus
• U.S. escaped major effects as one doctor (Kelsey) refused FDA approval

Thalidomide still being used to treat leprosy and plasma cell myeloma
• Tranquilizer, pain-killer, etc. eased effects of morning-sickness in pregnant women.
• Responsible for over 12,000 babies in 46 countries born with phocomelia
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National Research Act (1974)

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

The Institutional Review Board (IRB)

The Belmont Report (1979)

Congressional Legislation
National Research Act (1974)

Ethical Principles and Guidelines for the Protection of Human Subjects of Research

The Institutional Review Board (IRB)

The Belmont Report (1979)
1. Autonomy
2. Beneficience
3. Justice

1. Respect for persons: protecting the autonomy of all people and treating them with courtesy and respect and allowing for informed consent; Be truthful, no deception
2. The philosophy of "Do no harm" while maximizing benefits for the research project and minimizing risks to the research subjects
3. ensuring reasonable, non-exploitative, and well-considered procedures are administered fairly (the fair distribution of costs and benefits to potential research participants) and equally.
• Oath of Hippocrates (4th c BC)
• Nuremberg Code (1947): human experimentation
• Declaration of Helsinki (1964) - World Medical Association
  • Human experimentation
  • First serious attempt of medical community to regulate itself
• Declaration of Geneva (1948)
  • Issued as a development on the Oath of Hippocrates
• CIOMS Guidelines (1993)
  • Council for International Organizations of Medical Sciences
  • ‘International Ethical Guidelines for Biomedical Research Involving Human Subjects’
• Universal Declaration on Bioethics and Human Rights (2005)
  • UNESCO - United Nations Educational, Scientific, and Cultural Organisation
Resulted from “The Nazi Doctors Trial” of 1946-47

• Informed consent must be obtained without coercion
• Scientific experiments must be necessary and yield fruitful results for the good of society, unprocurable by other methods or means of study
• The experiment should be based on the results from animal experimentation
• The experiment should be conducted to avoid physical and mental suffering
• No experiment should be conducted where there is reason to believe that death or disabling injury may occur
• The human subject should have the right to withdraw at any time during the experiment without penalty
• If the scientist conducting the experiment has, at any time during the experiment, reason to believe the experiment may end in injury, disability or death to the experimental subject, he is obligated to stop the experiment.
Developed by the World Medical Organization in response to the Nuremberg Code

It is the first significant effort of the medical community to regulate itself.

Concern for the interest of the participant must prevail

Informed consent is a central requirement for ethical research

Declaration of Helsinki (1964)
• Opinion – Only two opinions really changed much

• Multiple Choice – Emotionally charged information was remembered more than
Multiple Choice – Emotionally charged information was “remembered” better than Codes and Declarations
Which of the following was not one of the three key points added to the Helsinki Declaration?

1. Established specific requirements for informed consent
2. The interest of the subject has higher priority than society
3. Every subject should get the best known treatment
4. Independent reviews of all human subject research are required
HeLa cells are a specific cell line that

1. Have been growing in labs since 1951 and are considered immortal
2. Were used in the Nazi Medical War Crimes in 1936
3. Are grown from rat ovaries and used for fertility research
4. Were used to “treat” syphilis patients in 1940
• Two weeks is too long!
• Case Studies are too complex
  • Student vocabulary is limited
• Discussions should be teacher-led, not student led.
  • Students tend to focus on one central notion, rather than the big picture
  • They aren’t so good about arriving at a “conclusion”
• Vocabulary!
• Introduce Bioethics with the PowerPoint (a few days MAX)
• ONE case study (not two) and develop class list of variables involved in the issue so that students can see the “big picture”.
• Incorporate ethics throughout the year and associate them with appropriate labs
  • Ex. pGLO with GMO’s
Please....?

Suggestions?
Title: Teaching Bioethics in a Standard First Year Biotechnology Class

Kathy Savage, Chemistry Teacher
Oviedo High School
601 King Street
Oviedo, FL

“One can be no better a teacher than one is a learner at any point in one’s life.” Paul Saltman

Abstract: This lesson was an attempt to teach a brief history of ethics and promote civil discussion of some ethical issues among first year low-level biotechnology students. Students were given an opportunity to reflect on their own preconceived notions of what is ethical as well as to share and discuss their ideas with their classmates based on two historical case studies. Students were given a pretest and posttest over both factual data and over ethical and moral terms and asked to rate them as to their relevancy in an ethical discussion. While the results showed that students did learn something about the history of ethics and also that some of them changed their views on the relevancy of specific values in ethical discussion, they were bored and frustrated with the lesson overall. The group discussions were beyond what could be expected of students at this age and level.

Rationale: Students are becoming more aware of the increasing number of bioethical issues that face our nation and the world every day. Questions regarding the ethicality of topics such as cloning, stem-cell research, and genetically modified organisms will, no doubt, come up at some point during the course of the school year in a course on biotechnology. As students begin to better understand the science as well as the techniques used in these fields, we need to prepare them to understand the dilemmas faced by researchers and politicians as they struggle to agree on the ethical standards that societies must obey.

As my Biotechnology students and I discussed the first PowerPoint of the year, “What is Biotechnology and what can it be used for?”, questions immediately arose from the students regarding certain ethical issues. The students seemed animated and anxious to share their opinions on topics such as cloning and stem cell research. I recalled the presentation by Ray Moseley, Ph.D. and his comment that there was a “difference between rational opinions and rationalizing opinions”. I quickly realized that my students not only needed some introductory education to ethics, but would welcome it.

Goals: The National Institute of Health (NIH) and the National Science Teachers Association (NSTA) states four possible goals for teaching bioethics in a classroom; 1) to advance science understanding, (2) to prepare students to make informed, thoughtful choices, (3) to enhance respectful dialogue among those with diverse views, and 4) to cultivate critical-reasoning skills. These goals can be viewed in the webinar located on the NSTA’s Learning Center website. I believe that all of these goals must be kept in mind as the main objectives for teaching ethics.
**Science Standards:** These goals meet at minimum the following set of benchmarks in Florida’s Next Generation Sunshine State Standards for grade levels 9 -12.

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<tr>
<td>SC.912.L.16.10</td>
<td>Evaluate the impact of biotechnology on the individual, society and the environment, including medical and ethical issues.</td>
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<tr>
<td>SC.912.N.1.4</td>
<td>Identify sources of information and assess their reliability according to the strict standards of scientific investigation.</td>
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<tr>
<td>SC.912.N.2.2</td>
<td>Identify which questions can be answered through science and which questions are outside the boundaries of scientific investigation, such as questions addressed by other ways of knowing, such as art, philosophy, and religion.</td>
</tr>
<tr>
<td>SC.912.N.4.1</td>
<td>Explain how scientific knowledge and reasoning provide an empirically-based perspective to inform society’s decision making.</td>
</tr>
<tr>
<td>SC.912.N.4.2</td>
<td>Weigh the merits of alternative strategies for solving a specific societal problem by comparing a number of different costs and benefits, such as human, economic, and environmental.</td>
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**Students:** There were 43 students in two separate classes. These were the first two classes of my day. The first class had 25 students and the second class had 18 students. These are low level students that are in standard (non-honors) classes. 19 of them are in remedial math and reading classes and 7 of them have IEP’s and take their tests and quizzes in the testing center where they are allowed extra time. 22 of them are sophomores, 15 are juniors, and 6 are seniors. One of them dropped the class during this project and one of them was removed and put in Operation Diploma which is a program for students at risk of dropping out (even though he was only a sophomore). Three of the seniors and one junior were placed in this class because the honors class was full with the 25 student limit and there was no place for them to go. This was a very intimidating situation for the lower-level students.

**Action Research Intervention:** The lesson involved two modules. The first module was a lecture/ discussion based on a PowerPoint (attached). The PowerPoint included a brief overview of some of the more renowned historical cases of ethical misconduct and the evolution of our current national policies on human research. The lesson also included a discussion of vocabulary and some ground rules for discussing ethical issue in class. The second module involved breaking the students into groups and allowing them to discuss two separate biotechnical ethical questions. The first question was whether or not a country or nation should financially benefit from bacteria that can be found only within their boundaries. The specific example used was that of an enzyme extracted from an extremophile in Lake Nakuru, Kenya in the 1980’s. The enzyme was sold to Genencor International, a company with close ties to Proctor & Gamble. The students read the article, “Who Benefits from African Research?” by Christine Gichure. (This article can be found online at the website listed in Literature Cited below). The second question was whether or not individuals should financially benefit from medical research that used their DNA or cells. The specific example was that of HeLa cells which were extracted from a tumor in a woman by the name of Henrietta Lacks in 1951. The students read Rupert Cornwells’ article “The Incredible Story of the Most Important Woman in the History of Modern Medicine.” (This
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Day Eight: Review & Conclusions

Day Nine: Post Survey and Post-test
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Data Collection and Analysis: There were two types of data collected from this research. The first was the pre-and post-test of ten multiple choice questions. This was a criterion-referenced test rather than an opinion test. This was the easiest to evaluate. I used the mean and median to evaluate the learning gains of the 43 students together as a single “class”.

43 students took the pre-test with not a single student passing. (60% or better is considered passing). The mean and the mode were both 20%. The only question that the class passed with a 62% was the last question on an ethical way to frame a question on abortion. This was one of two “value” questions on the test, rather than fact-based historical questions from the PowerPoint lecture. After the lecture and discussions, 32 of the remaining 41 students who took the test passed with a 60% or higher. The mean was a 60%, while the mode was a 70%. Question #4 (from 10% passing to 14%) and #6 (from 18% passing to 19% passing) showed the least improvement, while question #5 (from 13% passing to 84% passing) and question #8 (from 21% passing to 89% passing) showed the most improvement. This indicated that the students showed the least interest in the legal aspects of the historical development of our current ethical laws, but were more interested in the more tragic human stories that led to these laws. This was borne out by their comments to me at the end of the lesson. Over-all, they did not like learning about ethics and found it “boring”.

The second piece of data collected was the pre-and post-survey. This was used to see how students view the term “ethics” with respect to other nearly synonymous terms and to see if their opinions changed over the course of the lesson. For this survey the median scores of a 4-point Likert scale test will be used to determine shifts in attitude.

Surprisingly this survey saw little to no shift in opinion for any of the terms that was of any statistical value. Virtually the same number of students who saw “theistic values” as being a “highly relevant” part of ethical debate before the lesson viewed it as “highly relevant” after the lesson. The same was true for the term “democratic majority”. To me, these were the two terms I would have hoped to see the biggest shift in, along with “personal opinion” and “societal tradition”. Sadly, this was not the case. I attribute this to a rampant apathy among the students in my class. They turn their work in with as little done as possible and frequently what is done does not make any sense at all. Over-all, they are not taking this class seriously. In all of my eighteen years I have never felt as discouraged by the attitudes of the students as I feel this year. I think
that a scattershot approach was probably taken with the survey and since it was completely random before and after, the results looked the same.
Literature Cited:


"Dealing with Charged Topics in the Classroom," audio [podcast] from a fall 2005 Berkeley Topics on Teaching event. Professors Mark Brilliant, History, Kristin Luker, Sociology, and Rich Muller, Physics discuss their approach to teaching and dealing with what can be difficult topics.


**Budget and Budget Justification:** There were no costs associated with this lesson other than possibly printing off class sets of the situational examples or other articles for students to read. The pre-and post-tests as well as the surveys were done on the computers in the computer lab through Blackboard.

**Permissions:** I did not need permission from parents or students for this research, however, I did make my Assistant Principal and Principal aware of my research plans.

**Modifications:** I would not do this lesson plan again for three reasons. First, I believe the case studies were much too advanced for the type of students I had in my classes. In fact, these case studies were probably more appropriate for a college level class. The second reason is that I don’t believe my students work well in small group discussions where they are partially
responsible for monitoring themselves. They are not mature enough nor are they motivated enough to do so. The third reason that I would not do this lesson plan again is that it is too long. Since the students obviously found ethics “boring”, it should probably be something that is done in small bites throughout the year rather than in one big chunk. This project clearly seems to be a case of my own enthusiasm getting the better of me.

When we presented our projects at UF, the other teachers were so kind and offered many websites for lesson plans on bioethics that have already been developed that they felt were very good. I should not have tried to reinvent the wheel. It was very difficult to keep going with because even as I was presenting the lesson I could see that it was failing miserably and that students were not seeing it with the same eyes that I had hoped. It is painful to keep teaching when you have worked hard on a lesson that you are emotionally invested in and to see students bored out of their minds because they just don’t get what it’s all about. They seemed to focus on silly things like, “If we cloned Neanderthals, we could use them to do our chores for us!” and then would never come back to the reality of the situation. More maturity was definitely in order for a lesson of this magnitude.

**Dissemination:** I have praised this program at every in-service and county workshop we had this year. This summer I will be returning with at least two people from our county, Amy Demins and Kim Dahl. I haven’t shared much about my action research because it didn’t turn out so well, but I have shared labs and other ideas that we did last summer with other teachers. We also use many of the lab ideas in our biotechnology classes at Oviedo High School and they have worked quite well. I would be happy to speak at a conference or other meeting.

**Pre–Survey / Post-Survey:** Identify each word or phrase below as being highly relevant to an ethical discussion on whether or not we should allow human cloning or not at all relevant to the discussion. Put an “x” in the box you feel most closely identifies with your assessment.

<table>
<thead>
<tr>
<th>Benchmark Number</th>
<th>Benchmark Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>SC.912.L.16.10</td>
<td>Evaluate the impact of biotechnology on the individual, society and the environment, including medical and ethical issues.</td>
</tr>
<tr>
<td>SC.912.N.1.4</td>
<td>Identify sources of information and assess their reliability according to the strict standards of scientific investigation.</td>
</tr>
<tr>
<td>SC.912.N.2.2</td>
<td>Identify which questions can be answered through science and which questions are outside the boundaries of scientific investigation, such as questions addressed by other ways of knowing, such as art, philosophy, and religion.</td>
</tr>
<tr>
<td>SC.912.N.4.1</td>
<td>Explain how scientific knowledge and reasoning provide an empirically-based perspective to inform society’s decision making.</td>
</tr>
<tr>
<td>SC.912.N.4.2</td>
<td>Weigh the merits of alternative strategies for solving a specific societal problem by comparing a number of different costs and benefits, such as human, economic, and environmental.</td>
</tr>
</tbody>
</table>
Bioethics
Pre-test/Post-test:

1. Which of the following is not a characteristic of an “ethical” value? a) Humane b) Legal c) Good d) Right
2. Which of the following is not one of the three vulnerable research subjects as established by the “Common Rule”? a) Pregnant Women b) Prisoners c) Children d) The Elderly

3. The National Research Act of 1974 was passed as a result from the publicity of the a) Nazi Medical War Crimes b) Willowbrook Hepatitis Studies c) Tuskegee Syphilis Experiments d) San Antonio Contraceptive Studies

4. Which of the following was not one of the key points added to the Helsinki Declaration? a) Established specific requirements for informed consent b) The interest of society has higher priority than the individual c) The investigator’s duty is solely to the patient d) Ethical considerations must always take precedence over laws and regulations

5. Thalidomide is a drug that was used for/as a) Treating syphilis b) Treating morning sickness c) Treating baldness d) Birth Control
6. The Nuremberg Code or the International Code of Research Ethics includes all of the following requirements for experiments except: a) All drugs used for experimentation must have FDA approval b) Voluntary and informed consent c) Experiments must be scientifically necessary d) The right to withdraw without penalty

7. Which of the following is not one of the three bioethical principals? a) Autonomy b) Beneficence c) Integrity d) Justice

8. HeLa cells are a specific cell line that a) Have been growing in labs since 1951 and are considered immortal b) Were used in the Nazi Medical War Crimes in 1936 c) Are grown from rat ovaries and used for fertility research d) Were used to “treat” syphilis patients in 1940

9. “I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon’s knife or the chemist’s drug.” is part of a) The Hippocratic Oath b) The Common Rule c) The Belmont Report d) The Helsinki Declaration

10. Which of the following an incorrect way to frame an ethical question? a) Is it wrong to murder a two month old fetus? b) Should a three month old fetus be considered a child? c) At what stage in a pregnancy should abortions no longer be allowed? d) Does a three month old fetus have a developed nervous system?
Rupert Cornwell: The incredible story of the most important woman in the history of modern medicine

Out of America: Millions of tons of immortal cells – all grown from a single tissue sample taken from Henrietta Lacks before her death from cancer in 1951 – are used by researchers around the world, amid a debate about ethics, race and the rights of donors and their families

Sunday, 7 February 2010

She was a poor black tobacco worker, the descendant of slaves. She is buried in an unmarked grave in a clearing, just outside the little town in rural Virginia where she grew up, now all but razed from the face of the earth. Whether or not her soul lives on is a matter of religious belief. Unarguably though, her body does, and for that reason, Henrietta Lacks may be the most important woman in the history of modern medicine.

Her death in October 1951 from cervical cancer, in a public ward for "coloreds" at the then-segregated Johns Hopkins hospital in Baltimore, was both agonising and unnoticed – as routine in its way as the excision by a surgeon a few months before of a small sample of tissue from the malignant tumour in question. The sample was taken to a lab, and called HeLa. The name, as was customary, was taken from the first two letters of the donor's names.

Hitherto, no human cells had grown in culture. But Henrietta's cancer cells were different. They would not stop growing. More than half a century on, HeLa remains an inexhaustible source of living cells for testing, a priceless tool for medical research around the world. They were crucial for the development of the polio vaccine, and have contributed mightily to advances in the fight against cancer, to gene mapping and the study of diseases from leukaemia to Aids. They have been sent into space and one day may help us discover that medical Holy Grail, a cure for cancer.

In all, countless trillions of cells have been produced. If they could somehow be put together, it has been estimated, they would total millions of tons – a quite inconceivable figure given that thousands of cells can fit into the full stop at the end of this sentence. Not bad, as a physical measure of immortality, for a woman who when she died at the age of 31 was hardly five feet tall.

On scientific grounds alone, the story of HeLa would be extraordinary. But in science like the rest of life, context is everything – and that context is if anything even more gripping than the story itself. Henrietta and her family have been written about before, and a dozen years ago the BBC made a documentary about her, called The Way of All Flesh. But a stunning book published last week is surely the definitive work on the subject. At one level, The Immortal Life of Henrietta Lacks by Rebecca Skloot is a biomedical thriller. But it is far more: a case study of
race and medical ethics, of the problems that plague black society, and of how a family comes to terms with its past.

Not least, it recounts Skloot's own obsession with the Henrietta mystery, and her long effort to persuade her subject's children, above all Henrietta's daughter Deborah, to open up to a white writer as they struggle to come to terms with the reflected celebrity in which they so uncomfortably bask.

For humanity, HeLa has brought vast benefits; for Henrietta's family it has generated mainly turmoil and anger. Finally the ice is broken, and Deborah agrees to co-operate. "Get ready girl," she tells Skloot, "you've got no idea what you gettin' yourself into."

Henrietta had no idea when she died that her tissue was being used for research, still less that it had such miraculous properties; indeed, only in 1973 was she publicly confirmed as the source of the wonder-cells. That year, Henrietta's daughter-in-law, Bobbette, also learnt the truth, from the friend of a friend, who worked in cancer research and used HeLa cells routinely. "I ordered them from a supplier," he added casually, "just like everyone else."

"Just like everyone else." For Bobbette and the other Lacks, the implications of those words were terrifying. The infamous Tuskegee syphilis project, whereby black patients since 1932 had been the object of an experimental study without being told a cure – penicillin – existed for the disease, had only been shut down a year before. Once again, it seemed, poor and unwitting African-Americans were being exploited for medical research. The "night doctors" of legend, said to kidnap and murder blacks for this purpose, were stalking the land for real.

What happened to Henrietta and her cells broke no laws in 1951, and would break none today. US courts have ruled that an individual's consent is not required for his or her discarded tissue to be used for research. For its part, Johns Hopkins (which, unlike many white-run hospitals in those days, admitted black patients) felt that a sliver of tumour was a perfectly reasonable price for free treatment.

Nor did the hospital make money from its discovery. George Gey, the hospital's head of tissue research who discovered HeLa's properties, sent free samples to anyone who asked. These days, patients who know they have valuable tissue may set their price before it leaves their body; if they don't, then too bad. On the other hand, the biomedical companies that produce the stuff make money. Such is how capitalism works. Whether capitalism's sharing of reward is fair, however, is another matter.

Astonishingly, the Lacks have never sued for the rights to HeLa, even though Henrietta's children carry some of her DNA – and even though, years later, they were asked by Johns Hopkins to provide blood samples. They thought they were being clandestinely tested for cancer. In fact, it was to gain DNA data to tackle contamination problems caused by the prolific HeLa cells. But once again, those from whom the samples were taken were never told why.
After reading The Immortal Life of Henrietta Lacks, you can't help feeling that the people who provide the original raw material are being short-changed. These days, researchers can take out patents on genes and charge a small fortune for their use in testing. In 2001, HeLa cells, for instance, were running at $167 (£107) a phial. But Henrietta's descendants have never received a penny for her incalculable gift to science.

Life was not easy for any of her five children – least of all the youngest, Joseph, born a year before she died. A violent kid called "Crazy Joe" for his unpredictable ways, he was jailed in 1971 for 15 years for second-degree murder. In prison, he converted to Islam and changed his name to Zakariyya, but he never lost his resentment at what had happened to his mother.

"Them doctors say her cells did all this and that to help people," he complained to Skloot. "But it didn't do no good for her, and don't do no good for us. The only people that can get any good from my mother's cells is the people that got money, and whoever's selling them cells." Or as another of her sons put it, even more topically, "If our mother's so important to science, why can't we get health insurance?"

But ultimately, this is a story of a family coming to terms with itself, and the legacy thrust upon it. There are two especially poignant moments. In 2001, Deborah and Zakariyya finally visit the lab at Johns Hopkins to see some living cells traceable back to their mother, exactly half a century before. As they leave, even Zakariyya's anger dissolves, as he touches the doctor on the back, murmuring just "thank you".

A few days later, Deborah and Skloot set out to resolve one final mystery: the fate of Henrietta's fifth child, Elsie, an epileptic who died at the age of 15 in 1955, at what was once Maryland's Hospital for the Negro Insane. Today it is a well-kept school and community centre; then it was infamous for the overcrowding and squalor in which patients lived, and for primitive experiments conducted on their brains.

At first, the mission seemed hopeless; virtually all the hospital's records for the 1950s had long been destroyed. A few autopsy reports however survived – and amazingly one of them was Elsie's. Even more miraculous, attached to the page was a photograph, of Elsie being measured for height, seemingly screaming with pain, her head held in place by a pair of hands belonging to a white member of the staff. The picture was gruesome, but in its way it was closure. Just as Skloot's book represents a kind of closure for Henrietta Lacks as well.