GENE PATENTING WEBQUEST

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Do you know who owns your DNA? The race is on between Biotech Companies to research human genes because one new finding could lead to pharmaceutical advances worth millions. Courts have ruled that ownership of this type of information is legal. In this activity, you will be directed to a series of Internet sites to help you answer questions regarding the ethics of gene patenting.

**A. The Cases:**

# I. John Moore

<http://biotech.law.lsu.edu/cases/consent/Moore_v_Regents.htm>

Go to sections [14] – [33].

1. Who is being sued by John Moore?

2. John Moore is suing on what grounds?

3. What illness did John Moore suffer from?

4. Which organ was removed from Mr. Moore’s body? What was the reason given?

5. For nearly seven years following the operation, Mr. Moore was asked to return to the clinic for follow up testing. What was being done with the tissue samples?

6. What type of cells were patented in this case? Whose names are on the patent as “the inventors of the cell line?”

7. How much money did Genetics Institute agree to pay out for “exclusive access to the materials and research performed?”

 *II. Erich Fuchs and Steve Crohn*

<http://online.sfsu.edu/~rone/GEessays/WhoOwnsYourGenes.html>

8. To what disease is Erich Fuchs seemingly immune?

9. What research facility finally agreed to take a closer look at Mr. Fuchs’ case?

10. How does Mr. Fuchs’ immunity occur?

11. The scientists filed for a gene patent specifically for what?

12. According to Mr. Fuchs and Steve Crohn, what were their contributions to the research effort?

*Now check out this website to see the cellular reasons behind HIV immunity:*

<http://www.pbs.org/wnet/secrets/case_plague/interview.html>

13. What is the name of the mutation in the receptor that determines HIV susceptibility?

14. CCR5 is a receptor that allows HIV to enter the cell. Why is it OK that cells don’t necessarily have this receptor?

15. What other disease does this mutation protect humans against?

16. Which of the following groups would you predict would be most likely to be immune to HIV infection? Defend your position. African-Americans, Asian-Americans, or European-Americans.

*III. Daniel M. Greenberg and Sharon and Patrick Terry*

<http://online.sfsu.edu/~rone/GEessays/WhoOwnsYourGenes.html>

Scroll down to the section: The Families I, Searching for Good From Sorrow

17. With what disease was Mr. and Mrs. Greenberg’s children diagnosed? What are the symptoms? What is the average life span?

18. What contributions did Mr. Greenberg make to the research efforts?

19. Who now owns the patent on the gene? How much does a test for the gene cost?

20. What disease do the Terry’s children have? What are the symptoms?

21. What contributions did Mr. and Mrs. Terry make to the research efforts?

22. How did the Terry’s experiences with gene patents differ from that of the Greenberg’s?

# IV. Arupa Ganguly, Ph.D., University of Pennsylvania

[http://jncicancerspectrum.oupjournals.org/cgi/content/full/jnci;92/8/596](http://jncicancerspectrum.oupjournals.org/cgi/content/full/jnci%3B92/8/596)

23. BRCA 1 and BRCA 2 are genes associated with what medical conditions?

24. Who owns the commercial rights to the two genes?

25. What group is offered the test at a reduced rate? Why would Myriad Genetics do this?

26. What is the cost for each commercial (publicly used) test? What is the justification, according to Dr. Greg Critchfield, of this cost?

27. In 1998, Dr. Arupa Ganguly’s research was stopped by Myriad Genetics, citing an infringement on their patent. Who loses in this situation? **B. The Law:**

##### I. Intent of Patents

<http://www.nsgc.org/newsroom/position_dna.asp>

28. What group of professionals does NSGC represent?

29. What is the role of patents, according to NSGC?

30. What is the NSGC’s recommendation regarding royalty rates?

##### II. Gene Patent Law

<http://www.ornl.gov/TechResources/Human_Genome/elsi/patents.html>

31. What are the four criteria for any patent application?

32. At what point does DNA become patentable?

33. How long does a patent last?

34. What problem could researchers run into after they have initially filed for a patent?

35. What are some different types of genetic material that can be patented?

36. What are the four requirements specifically for genetic patents?

37. According to the Human Genome Project Information Website, “Patenting provides a strategy for protecting inventions without secrecy.” Why is this advantageous to patients? Why is this advantageous to the researchers?

38. Summarize the arguments cited for and against gene patenting.

C. What is actually owned??

###### I. An Introduction to Bioinformatics

<http://www.ncbi.nlm.nih.gov/About/primer/bioinformatics.html>

39. What is a biological database?

40. What are two major requirements for databases to be useful?

41. What is bioinformatics?

42. Is this bioinformatics database complete?

43. How can this website be used to support the theory of evolution?

44. What are some questions that can be answered by using Map Viewer?

##### II. Looking at the CCR5 Mutant for HIV Resistance

So, now that we have a general overview of the science of Bioinformatics, let’s try out this database by finding the nucleotide sequence for the CCR5, the HIV receptor. We are going to use an activity adapted from David Form from Minuteman Regional High School.

Go to: <http://www.ncbi.nlm.nih.gov/>

Step 1: In the upper left corner, Search “All Databases” is chosen for you. Change “All Deatabases” to “Gene.”

Step 2: To the right of “Gene”, you see a box. Type “CCR5” in the box.

Step 3: Press enter.

Step 4: Click on the first entry: CCR5.

Your new screen shows you a ton of information, but some of it can be useful to us here. For example, CCR5 is found on chromosome 3. The summary tells us that the protein is found on T cells and macrophages and is an important receptor for HIV.

Step 5: Scroll down to PubMed links under the Bibliography. This is a list of research papers written about CCR5.

Step 6: Continue scrolling down to “NCBI Reference Sequences (RefSeq).” Click on the hyperlink “NM\_000579” for the mRNA sequence.

Step 7: At the top of this page, they’ll tell you how many base pairs there are in CCR5: there are 3,686 bp’s. Following this, you’ll see a LONG series of papers discussing CCR5. You can scroll through all this for our purposes.

Step 8. Scroll down to the “CDS” section. Click on that hyperlink to change the CCR5 nucleotide sequence to just the coding sequence. (The beginning and the end of this strand of DNA is important for the structure of the protein, but not the function of the receptor, so we’re just going to look at the useful piece). The number of base pairs should change to 1,059 bp.

Step 9: Scroll to the “ORIGIN” section. These are all the nucleotide bases that make up the CCR5 gene. They are organized in groups of 10 base pairs and list all 1,059 bp.

\*\*This is the “recipe” for making the protein that is found on some immune cells that allows the entry of HIV.

Steve Crohn and Erich Fuchs have a mutation inherited from both their parents in this gene. It is called “CCR5 delta 32.” The reason behind the name is that the mutation has a deletion that is 32 base pairs. So the gene is no longer 1,059 bp. Predict the difference before actually completing this portion of the exercise.

Step 10: Go to <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=8751444>

Step 11: Enter ‘X99393’ into search box to right of PubMed .

 Then click on ‘See nucleotide sequence data.

At the top, middle of the page, above “Definition,” you can count how many base pairs there are in the coding region of CCR5 delta 32. Is it what you expected?

III. The Patents Themselves

We are now going to take a look at two gene patents discussed in this webquest. You’ll notice a couple of things immediately. First, they are INCREDIBLY LONG!! Don’t get intimidated by how much information is available. After all, you don’t have to decide whether to give them the patent or not. We’re just going to look at a couple of items. You’ll also notice that the companies do indeed have to know more about the gene than just the DNA sequence.

Go to: <http://dnapatents.georgetown.edu/>

Click on ‘Search’ upper left in blue 🡪

Click on ‘Basic search’ under U.S. Issued Patents (First column)🡪

 Enter ‘5679635’ in ‘Search Query’ box🡪

 Scroll down to find the patent entry:

45. What disease is associated with the information patented in this document?

46. Who is the “assignee” for this patent?

47. Who is noticeably absent from the list of inventors?

Now search for patent number: 5753441

48. What diseases are associated with the information patented in this document?

49. Who is the “assignee” for this patent?

50. When will this patent expire?