**Initial Case Study:**

…On a plane bound for Tijuana Mexico, Suzanne remembers the day she received a frantic phone call from her sister Karen about the news from her doctor:

 “The doctor says I have cancer!” she exclaimed. “He says it is an aggressive but treatable form of Lymphoma. I don’t even know where these cells are in my body and the disease might kill me!” Karen continued “I’m scared and I don’t know what to do. I don’t want to die Suzanne.” “Calm down Karen,” Suzanne remembers telling her sister, “we are going to beat this, don’t you worry. Everything will be okay.”

Although Suzanne succeeded in calming her sister, she remembers how she immediately jumped onto the computer and looked up “Mantle Cell Lymphoma” to start researching the best doctors, treatment plans, and options available. Suzanne recalls finding the best oncologist in the city to take Karen’s case…and how he suggested a very aggressive regimen of chemotherapy which should be started immediately.

Karen had taken only two of the aggressive chemotherapy treatments when she became very ill, had to skip a treatment, and ended up spending a week in the hospital. Disillusioned with the experience Karen then began looking for alternative treatments. She found a clinic in Mexico that claimed to specialize in the treatment of Mantle Cell Lymphoma, so she decided to try the alternative before continuing her previous treatment regime with her doctor in America.

Upon hearing of her sisters decision Suzanne was hesitant. “Karen”, Suzanne said, “I understand you are frustrated and scared, but I think you should give the conventional treatment more time”. However, Suzanne would soon discover that this advice had come too late for Karen; she had already contacted the clinic and booked a flight for the both of them to fly to Mexico. “I’m not sure this is a good idea”, thought Suzanne, “but how can I tell Karen no; I don’t know that I wouldn’t do the same thing if I were in her position”. As they flew on above the clouds, piercing the serenity one finds 30,000 feet above sea level, Suzanne’s mind finally yields to the stark reality of the situation at hand: “I just hope this not only cures her, but also gives her peace of mind” Suzanne suppresses her sudden enlightenment, until now she has been so preoccupied with the emotions and needs of her sister, but now her deepest fears gnaw at the fringes of her consciousness…“I’m just not ready to lose my only sister yet.” as she looked at Karen sleeping in the seat next to her.

 Karen and Suzanne arrived early evening at the clinic. As they began to settle in, their attention turns toward making sure they had all of the paper work in order. The last thing they want is problems with the records they need provide the nurse when she comes to take her information and vital signs. The wait seems immeasurable. Eventually the nurse does come, collects all the information, paper work, and money…then she promptly leaves.

“Well, I guess they will have you sign release forms and paper work in the morning” Suzanne commented. “Although, it seems odd to me that they would not have you complete everything tonight.” Karen’s response catches Suzanne by surprise, “I don’t care if they don’t have me sign a single paper. As long as the treatment works the way it is supposed to…it doesn’t matter to me what they do, or do not do, with regard to paperwork…or anything else.” Karen finishes her opinion with a look of peace and satisfaction.

“Surely you don’t mean that Karen.” Suzanne almost retorts. “I most certainly do” announces Karen, sitting erect and looking at her sister with conviction. “Why should I care about release forms and such? I have already completed my fill of release forms back in America. Besides, what purpose do they really serve?” Karen continues as Suzanne looks on in disbelief with her sister’s obvious lack of forethought regarding the ramifications of her aloofness. “No one reads them; they just take up space in my file because I’m told this is all part of procedure to ‘keep people from suing’ if the treatment doesn’t work.” Karen now settles back into the lounge chair feeling purged of her initial angst about the subject, and now gazes peacefully from their balcony overlooking a beautiful beach.

“Karen, those papers are meant to protect you as much, if not more than, the doctors” Suzanne gently comments. “Your information could be used without your permission, or your knowledge, and if you don’t sign those forms you are powerless to do anything about it” Suzanne says with a look of concern. “What could they do with my information that would matter to me?” Karen asks impetuously. “They could use your cells for research without your knowledge.” Suzanne remarks sounding a little agitated. Karen’s subsequently casual reply, “I don’t care what they do with them as long as I am rid of them and treatment can begin” leaves Suzanne all the more disconcerted.

“Well, you should.” Suzanne says as she grabs her laptop. After a few minutes of hurried tapping on the keyboard, Suzanne then hands the laptop over to her sister… “Here, take a look at what can happen when people use your cells without your knowledge, or permission, and reap all the benefits from it without any credit or compensation to the donor.” Suzanne continues “Read the story of Henrietta Lack. She is probably responsible, at least indirectly, for many modern scientific procedures, most likely including the treatments you are about to receive…and she died penniless.” Karen took the laptop and started reading……

***Before you read the subsequent case which Suzanne has brought to Karen’s attention via internet resources, I want you to consider a few questions and possibly do some research to help you answer these questions. Formulate some ethical opinions based on your research …Then I will distribute the information Suzanne presented for you to consider.***

# Research Questions and Ethical Considerations:

# Can you brainstorm 3 possible things that might support Suzanne’s case prior to any research? If so write them down as a starting point.

# Use Google: ([Heath Care dilemma](http://www.issuesinmedicalethics.org/151cs31.html)), ([Cloning Dilemma](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Cloning)), ([Stem Cell Research](http://newsbatch.com/stemcells.htm)), or [Mr. Taylor’s Webpage: Ethical Considerations](http://mathandsciencewithmrtaylor.weebly.com/ethical-considerations.html), as a resource to research possible supporting examples of why Karen should be more protective of her biological property.

# What ethical problems can arise from unsecured biological resources?

# If you could not find any resources independently, use the sites with URL’s offered above and summarize what those sites contained *(only the part you are using to support your viewpoints)*. There should be a minimum of six supporting citations.

# When finished take 5 minutes to prepare to share out what you have found in a small group presentation as a “think-pair-share” activity.

**Terms to use or define as a guide to independent or extended research:**

* Gene Therapy
* Genetic Privacy
* Gene Ownership
* Proprietary Reimbursements
* Electrophoreses
* Karyotype
* Pedigree
* Inheritance
* Dominance and Recessive
* Discrimination
* Research rights
* Transparency / Disclosure