Lorenzo' s oil worksheet answers part 2



## Answer the questions below.

Choose **no more than five words and/or a number** from the text for each answer. For each question, write your answer in the space provided on your answer sheet.

1. It is unknown when the Mediterraneans fell in love with olives because it was

before \_\_\_\_\_\_.

2. The world's biggest olive oil producer is \_\_\_\_\_

3. Besides it is cheaper to harvest olives in the traditional way, many olive growers

do so because it is \_\_\_\_\_

People who come to help with the harvest gets paid \_\_\_\_\_\_.

Two uses of olive oil during ancient civilisations were as \_\_\_\_\_\_

6. Food like \_\_\_\_\_ can stay fresh using olive oil.

7. Frequently using olive oil has made the Mediterraneans have the \_\_\_\_\_ in

the western world.

8. Olive oil improves the lives of people when it is \_\_\_\_\_

Complete the table below with a word from the text. For each question, write your answer in the space provided on your answer sheet.

Meaning	Word
9. to press something very hard and break it	
10. to pick and collect crops	

## BLIVEWORKSHEETS

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1.1



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Lorenzo's oil part 2 worksheet answers

SUBJECTS — Medicine; Science; SOCIAL-EMOTIONAL LEARNING — Illness, Disabilities; Marriage; Families in Crisis; Parenting; Sisters; MORAL-ETHICAL EMPHASIS — Responsibility; Caring. AGE; 13+; MPAA Rating — PG 13 (for child's life-threatening ordeal); Drama; 1993; 135 minutes; Color. Available from Amazon.com. One of the Best! This movie is on TWM's list of the ten best movies to supplement classes in Science, High School Level. This is the almost true story of Lorenzo Odone, his parents, and their fight against a terrible disease, adrenoleukodystrophy (ALD). The tale begins in 1984 when Lorenzo, then age 5, is diagnosed with the disease. The doctors give him a prognosis of relentlessly increasing disability and death within two years. There is no treatment. The Odones do not accept this verdict and embark on a dramatic search for a way to save their son. Selected Awards: 1993 Academy Awards Nominations: Best Actress (Sarandon); Best Screenplay; 1993 Golden Globe Awards Nominations: Best Actress (Sarandon). Featured Actors: Nick Nolte as Augusto Odone; Susan Sarandon as Michaela Odone; Peter Ustinov as Prof. Gus Nikolais; Kathleen Wilhoite as Deirdre Murphy; Zack O'Malley Greenburg as the young Lorenzo Michael Murphy Odone; Gerry Bamman as Dr. Judalon; Margo Martindale as Wendy Gimble; James Rebhorn as Ellard Muscatine; Ann Hearn as Loretta Muscatine; Maduka Steady as Omuori. Director: George Miller. "Lorenzo's Oil" is an enthralling medical detective story. It can serve as a motivator in the study of the scientific method, chemistry, biology, neurology, and genetics. The film is an excellent introduction to the medical research establishment and the ethics of clinical trials. Merely watching this movie is a hard-hitting life experience. It teaches courage, persistence and that sometimes motivated people can achieve what the disabled are real people with feelings and intelligence. The film explores some of the problems in getting society to take note of and to address extremely rare diseases. The movie and this Learning Guide provide several opportunities to teach critical viewing skills. The movie contains a key factual error that provides an excellent opportunity to teach the scientific method. At the time the movie was released, scientific studies had demonstrated that Lorenzo's Oil did not work for other ALD patients who like Lorenzo, had already developed symptoms of the disease. Lorenzo's reaction to the Oil was an anomaly. (We are not aware of any explanation for why the Oil worked with Lorenzo.) The worries of the scientists and ALD Foundation leaders about holding out false hope to families (concerns that were ridiculed in the movie) turned out to be entirely justified. Then, in a twist of fate, scientific studies completed ten years after the film was made found Lorenzo's Oil to be effective in preventing ALD in a different group of people, boys with the ALD genetic defect who did not yet have neurological symptoms. Ironically, these studies were performed by Dr. Hugo Moser. In the movie, the character modeled on Dr. Moser, Dr. Nikolais, is portrayed as the epitome of the unresponsive medical establishment. TWM's Lesson Plan — The Development of Lorenzo's Oil, Strange Twists of Fate, and the Scientific Method uses these circumstances as the basis for an exercise in applying the scientific method and developing hypotheses in a real world situation. "Lorenzo's Oil" is most helpful if students are given a description of certain scientific and biological concepts Handout. TWM's scientific methods lesson plan provides a review of the process by which Lorenzo's Oil was discovered. If you can project images from the Internet onto a screen, the animation from the Myelin Project and the Diagrams of Four Fatty Acids will be very helpful. A Comprehension Test and Medical Ethics Test are also provided with this Learning Guide. SERIOUS. There are heartrending scenes showing Lorenzo's increasing disability and his coughing fits in which, unable to swallow, he chokes on his own saliva. The film may upset sensitive children. It may be a good idea to tell children as they watch this movie that it is a mostly true story, that Lorenzo, in the end, survives, although he is still seriously disabled, and that the Odones' efforts to save their son have allowed other children as they watch this movie that it is a mostly true story. productive lives. Some viewers may be distracted by Nick Nolte's heavily accented English. However, Nolte simply provides a fair rendition of how the real Augusto Odone sounds when he speaks English. See Roger Ebert's Review of this film for the Chicago Sun-Times. For children not strongly interested in science, review with them the key factual error described in the Benefits section. Then ask and help your child to answer the Quick Discussion Question. To the extent that you can, immediately after the movie, or at odd times over the next week (for example at the dinner table or in the car on the way to school) talk to them about the genetics of the transmission of ALD, why women don't get the disease but carry the gene, the difference between X and Y chromosomes, dominant and recessive genes, etc. See Lesson Plan: Predicting Combinations for Alleles in a Zygote Using Punnett Squares. If you have a child who is interested in science, review the entire Helpful Background section with him or her and go through each of the three lesson plans associated with this Learning Guide. ALD causes the loss of the white fatty insulating covering (myelin sheath) on nerve fibers within the brain. See diagram of a neuron showing myelin sheath. The disease also causes the progressive degeneration of the adrenal gland. Its basis is genetic. The ALD genetic defect is very rare, with a minimum incidence of one in every 16,800 births. ALD affects all races equally. Very long chain saturated fatty acids, VLCSFAs (see Diagrams of Four Fatty Acids), are normally found in blood plasma and other tissues of the body. In patients with ALD, VLCSFAs are not broken down by the body. These fatty acids accumulate in the brain and in the adrenal glands. By an unknown mechanism, perhaps an autoimmune response, this causes inflammation and the loss of myelin. (The name of the disease comes from "adreno" relating to the adrenal gland; "leuko" referring to the white color of the healthy myelin sheath; and "dystrophy" which means abnormal development.) Several other rare inherited disorders are also characterized by the loss of myelin. Multiple sclerosis is an example of an acquired disease which can destroy myelin. VLCSFAs have very long hydrocarbon chains (H-C-H). See Diagrams of Four Fatty Acids. Diet is one source of VLCSFAs. The body also makes its own VLCSFAs. Enzymes in the smooth endoplasmic reticulum add hydrocarbon units (H-C-H) to the chains of shorter fatty acids. (The endoplasmic reticulum is a highly convoluted membrane within cells which makes proteins and lipids. Lipids are molecules that do not dissolve in water, such as fats. In the movie, Augusto Odone used paper clips as a model for links in the hydrocarbon chain.) In normal individuals, VLCSFAs are kept at safe levels by peroxisomes in the liver which oxidize excess VLCSFAs. ALD is caused by a defect in a gene which prevents the body from making the enzyme that break down various lipids.) ALD affects only males. It is caused by a defect in a recessive gene on the X chromosome. (See Lesson Plan - Predicting Combinations for Alleles in a Zygote Using Punnett Squares.) Symptoms appear in boys between the ages of 4 and 8 and may include behavioral changes such as poor memory, loss of emotional control, and dementia. Other symptoms are muscle weakness, difficulty in walking, spasticity, as well as deficiencies in vision, hearing, and speech. Progression of the disease brings deteriorating muscle tone, difficulty in swallowing, and eventually onset of coma. The disease brings deteriorating muscle tone, difficulty in swallowing, and beath. It is now possible to determine if the defective gene is present in boys before the onset of symptoms and in females who are less than 6 years old, do not have neurological symptoms, and who have a normal MRI (magnetic resonance imaging scan) of the brain. It is strongly recommended for this group. Adrenal insufficiency. Bone marrow transplants help boys and adolescents with early brain involvement, however, risk of mortality and morbidity is high for this treatment. Bone marrow transplants are not recommended when symptoms are already severe. Symptomatic and supportive treatments for ALD include physical therapy, psychological support, and special education. As of 2005, researchers believe that the inflammatory/autoimmune process is the best avenue for finding a cure for the disease. New methods of immunosuppression are under active investigation. The prognosis for ALD, which affects approximately 35% of children with the defective gene, is poor. Death usually occurs one to ten years after symptoms appear. Because ALD is so rare, the availability of public and private funding for research is limited. The movie traces the steps in discovering Lorenzo's Oil. It can be used to show the scientific method in operation. THE SCIENTIFIC METHOD See Lesson Plan — The Development of Lorenzo's Oil, Strange Twists of Fate, and the Scientific method is the process by which scientists find answers to questions about the physical world. The physical sciences such as physics and chemistry usually use experimentation. In this Learning Guide, we will discuss experimentation. Science recognizes that what actually happens in nature is the only measure of scientific truth. In science: "phenomena is king." The scientific method has four steps: research that explores the current knowledge on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be
described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is an educated guess based on the research (hypotheses must be described in terms that can be tested experimentally); the latter is a designing and conducting the experiment; and reaching a conclusion. The scientific method can also be summarized as developing a hypothesis (steps 1 and 2) and then testing it through experimentation or observation (step 3). Based on the experiment the hypothesis will be tentatively accepted as true or shown to be false (step 4). The hypothesis may be modified based on the results of the experiment and additional research. A hypothesis is a tentative explanation in the natural world which can be tested through experiments or observation. A scientific hypothesis is not really proven true or correct. It can be rejected because it is determined to be inconsistent with the data. If experiments or observations are consistent with the hypothesis (for example if the predictions that logically flow from the hypothesis until new evidence either finds it to be faulty or until many experiments over a long period of time confirm it. But even then, the hypothesis is always subject to revision if new data, such as new or more accurate tests, are developed. A basic assumption of all science is that changes in physical phenomena have a cause which, after careful research and experimentation, may be determined. The best hypotheses are stated in terms of a cause and a resulting effect. For example, oil and water will separate when put together. They will not combine into one liquid. (A liquid in which two compounds combine, such as oil and water, is called an emulsion.) The hypothesis would be stated as follows: "Soap added to oil and water in a container will cause the oil and water to combine into an emulsion." The control for this experiment is that instead of adding a certain amount of soap, you add that same amount of oil and water, see How Soap Cleans. In designing experiments to test a hypothesis, the factor which you change or which you introduce is called the "independent variable." (In our example, the independent variable." In our case, the dependent variable." (In our example, the independent variable." In our case, the dependent variable." soap, changes into an emulsion. To put it another way, the independent variable is the one the scientist changes to see what the result will be. The dependent variable is what changes in response. In designing experiments, we want to have only one independent variable is the one the scientist changes in the dependent variable is what the result will be. variable. Very few hypotheses can be stated without assumptions. An assumptions. An assumption is really a hypothesis that the researcher feels comfortable in making. Scientists discourage assumptions. An assumption is really a hypothesis that the researcher feels comfortable in the design of any experiment. A model seeks to explain a natural phenomenon or process in graphic terms. Models are useful when they help scientists develop new hypotheses. In the case of Lorenzo's Oil, the model of the sink with two taps and a clogged drain helped scientists and the Odones think about what had to be done to lower the level of VLCSFAs in the bodies of children with ALD. Another model is the idea that atoms have valence shells that have a certain number of electrons in them and which need a certain number of electrons to be stable or "happy." A scientific theory is a group of related hypotheses which have been confirmed through repeated experiments or observation and which provide a coherent explanation for a large number of natural phenomena. Theories are internally consistent, have survived repeated tests, and are helpful in problem-solving. Examples include Newton's "clockwork" universe, the cell theory, and the theory of biological evolution through natural selection. On occasion, a scientific theory will be discarded or modified. This occurs when new observations cannot be explained by the theory. Scientists will then try to come up with a new theory that takes account of all of the provisionally confirmed hypotheses and the new data. An example is what happened to Newton's clockwork universal gravitation, were first enunciated in 1687. They were shown by repeated experiments to accurately predict natural phenomena. They came to be accepted as laws of the natural world. However, as science progressed, there were some new observations that didn't seem to gibe with Newton's laws. In 1915, Albert Einstein showed that his theory of relativity fit more closely to the facts especially at speeds that approached the speed of light. While Newton's laws of motion had been repeatedly confirmed in experiments and are still adequate for speeds that do not approach the speed of light. of a hypothesis is whether it will predict or describe events in the real world. No matter how much we might cherish the hypothesis, if it doesn't consistently predict phenomena, it must be revised or rejected outright. For this reason, the scientific method requires that the researcher be rigorously honest in reporting the results of his experiments, even if those results contradict his long-held beliefs. APPLYING THE SCIENTIFIC METHOD TO THE DEVELOPMENT OF LORENZO'S OIL THE STORY OF A THERAPY THAT WORKS ... BUT NOT FOR THE PEOPLE FOR WHOM IT WAS DESIGNED See Question and Answer Based Lecture in Lesson Plan — The Development of Lorenzo's Oil, Strange Twists of Fate, and the Scientific Method. There are two additional points about Lorenzo's Oil. First, it doesn't treat the cause of the disease, which is the body's failure to make a protein necessary to transport VLCSFAs to the peroxisomes in the liver. It lowers the concentration of VLCSFAs by reducing the rate at which they are formed. (In the model of the sink with two taps and a clogged drain, Lorenzo's Oil closes the biosynthesis tap. A cure for ALD would open the drain by allowing the body to take the VLCSFAs even when treated with Lorenzo's Oil. Second, there are side effects to taking the oil For example, Lorenzo's Oil reduces platelet count (thrombocytopenia). The side effects, however, are not nearly as damaging as the disease that is called ALD. Most remain unaffected until adulthood, most developing adrenomyeloneuropathy (AMN) between the ages of 21 and 35. AMN is a milder form of ALD that affects the long tracts of the spinal cord but does not develop into the cerebral inflammatory disease. People with AMN can survive into their 80s. Symptoms include leg stiffness, difficulty with walking due to spasticity, urinary disturbances, impotence, cognitive defects, emotional disturbances, and depression. Neurological disability occurs slowly over several decades, which differs from the rapid deterioration that occurs in the cerebral disease. About 5% of teenagers or adults develop an inflammatory cerebral disease. symptoms in their later years. These symptoms include partial paralysis of the legs, moderate sensory loss, urinary problems, and peripheral neuropathy. Scientists don't know why some children get ALD while some adults get AMN. Why were the doctors so conservative and unwilling to take risks? One of the main principals of the medical profession is to do no harm. This means that physicians should not interfere in the normal processes of the body unless they know that their intervention will be beneficial. There are two basic reasons for this doctrine. First, the body in many cases will heal itself. Second, the history of science and the work of every scientist abounds with examples of hypotheses that made a lot of sense but which didn't work when tested. Many treatments that were once relied upon by medical science have turned out to be harmful rather than helpful. (Remember bleeding people to relieve the "humors" in their blood?) Many drugs or medical devices, once thought to be safe, have been withdrawn from the market after causing death or injury. Examples are IUDs, thalidomide and Vioxx. It is for this reason that federal law, administered by the Food and Drug Administered by the Food administered by Lorenzo's Oil on their son was that the Odones had not complied with any of the codes of ethics to testing drugs on human beings. The first code of ethics for physicians conducting research on human subjects arose out of the Nuremberg War Crimes Trials. Nazi doctors had performed inhumane
and often deadly experiments on thousands of concentration camp prisoners. Examples included: injection of foreign substances such as gasoline; immersion in ice water; and forced ingestion of poisons. Seven physicians were sentenced to death and another 16 were given prison sentences. (For a movie about the trials of judges and lawyers who participated in Nazi war crimes, see Judgment at Nuremberg.) In their verdict against the doctors, the Nuremberg Code. Abuses of subjects in clinical trials have not been confined to Nazi Germany. In the U.S., black men involved in a study of the effects of syphilis were denied effective therapies for decades so that scientists could watch the natural course of the disease if it went untreated. In 2005, the U.S. Environmental Protection Agency (EPA) proposed to study the effects of the use of insecticides known to be dangerous to children by giving video cameras and money to families (mostly poor families) who used the insecticides. The parents were to record the effects of insecticide exposure on their children. The plan was only dropped when two U.S. Senators blocked President Bush's nominee to head the EPA and would not permit a vote on the insecticides. relating to clinical trials are strict because a desire for career advancement or financial gain might lead scientists to take unnecessary risks with the lives of patients. Problems in this area are especially acute with drugs, once thought to be safe, are pulled from the market when more extensive research shows that they have unacceptable side effects. In 2004/2005, the National Institutes of Health was rocked by a scandal when it was disclosed that scientists making recommendations for treatments were also taking consulting fees from the companies which made drugs. used in those treatments. (For example, it was reported that two-thirds of the members of a panel that made recommendations that resulted in increased use of certain drugs.) For the above reasons, scientists are trained not to gamble with human lives. Ethical scientists (the vast majority) will not perform clinical trials on human beings until the procedure has been checked and rechecked and until trials using animals have been successful. Clinical trials using animals have been successful. Clinical trials using animals have been successful. safety monitoring; and (4) continuing review by an independent review board. The Odones were Not Doctors and Had No Time Obviously for the Odones, trying anything was better than just watching while Lorenzo died. In addition, they had no conflict of interest (the ambition for fame or fortune) that might affect the judgment of a scientist. The Odones were aware that many promising treatments (many hypotheses) didn't work out as expected. They knew about the animal studies in which erucic acid had caused heart disease in rats. (Before trying the erucic acid on Lorenzo, Deirdre (Micheala's sister) took it for a short period.) The Odones were incredibly lucky to find a therapy on the first or second try that did more good than harm. The doctors wanted the Odones said that: We respectfully claimed the right to have an independent mind and to study everything available in the literature, formulate hypotheses and test them. Interestingly enough, they turned out to be true. [The researchers] believe that science has its own pace and they believed it's a bit leisurely. .... Our message to parents is: realize that your interests and the doctors' interests are not parallel. You may have a motivation and a time limit that these people do not have "Lorenzo's Oil: A Movie Outruns Science" New York Times, Feb 9, 1993, by Gina Kolata. Why the Doctors Were Hesitant About Lorenzo's Oil After It Had Worked on Lorenzo's Oil to immediately be made available to every ALD child The doctors complied with this request. (Dr. Moser said it took only 30 days to get approval for an open clinical study of Lorenzo's Oil.) However, the doctors refused to advocate Lorenzo's Oil as a proven treatment because the Odones' evidence was only anecdotal. Evidence that comes from the experience of one or several individuals and is not based on scientifically designed experiments is called anecdotal. Often anecdotal evidence turns out to be an anomaly or based on some set of facts that are not disclosed. Scientists are taught to be very suspicious of the progression of the disease. It turned out that Lorenzo's case was an anomaly. Lorenzo's Oil does not consistently work with children who have already developed neurological symptoms develop and when the children have a normal MRI. He was elated to find that Lorenzo's Oil is an effective preventive therapy for ALD. The irony is that, except for Lorenzo is the disease. Genetic counseling informs parents before the wife gets pregnant about the chances of the child having genetic defects. All couples in which the woman is a carrier of the ALD genetic defect should think very carefully about adoption as an alternative to having biological children. Adoptive parents form bonds with their children which are as strong as the bonds of biological parents. There are also programs in which women with no known genetic defects agree, for a fee, to be artificially inseminated. The child is then adopted by the wife of the father and raised as the couple's own. Males with the ALD gene who live into adulthood will not have male children will at least be carriers. If the mother is also a carrier (and the father has the ALD genetic defect), 50% of the daughters will be females with ALD. (This is Punnett Squares.) Adoption is an excellent alternative for people with defective ALD genetic defect. The film is based on real events which are powerful on their own. However, the filmmakers have added to the emotional power of the story by a number of literary and cinema. The dominating story of Lorenzo's Oil is the struggle of man against a heartless nature, in this case, ironically, Lorenzo's and Michaela's own genes. The human struggle against the elements is a basic fact of life, cushioned for modern man by the wonders of technology and advanced social organization. But, ultimately, death claims us all. A second theme, and a common concern in Western culture is the struggle of individuals with no power (or small groups of people, such as families with no power) against large institutions. In this instance, the medical research establishment was not responding to the desperate need of ALD families. Because ALD affected so few people, resources were allocated to study other diseases. When the Odones tried to do the research themselves, they ran up against the ethical rules restricting clinical trials. However, without these rules, serious abuses can occur. (See Ethics in Medical Research section.) The third important storyline links Lorenzo to the crucified Christ who suffered for the salvation of others. (This could also be referred to as a symbol that runs through the film and has several aspects.) Clustered at the beginning of the movie are scenes of the Madonna and Child. "Many of the scenes of Easter mass are shot from high above, focusing first on the priest and his acolytes; then, moving in closer, on the heads of Michaela and Augusto, never again at mass but often, in turn, as they are doing research in the library of the National Institutes of Health in Bethesda, a secular cathedral to science ...." Late in the film there is a scene which brings the religious imagery into focus when Augusto Odone says to his theme with images of a church ceiling showing frescoes of angels and cameo shots of several young boys with ALD attesting to their well-being due to Lorenzo's Oil. " Medicine and the Movies: Lorenzo'Oil at Century's End Anne Hudson Jones, Ph.D., quotation beginning with "Many of the scenes ..." has been taken from this article. A fourth, actually a set of storylines, are the subplots relating to the family members and friends who help the Odones. There are true aspects to many of these. Omouri really did come from Africa to help his friend Lorenzo. Deirdre came to help and submitted herself as a guinea pig. Don Suddaby, the chemist in England really existed (and played himself in the movie). We don't know how much the filmmakers kept to the literal truth in the subplots about the other friends, the workers in the chemical factory, and the librarian, but certainly these ring true. From the standpoint of critical viewing, it is important to note that these subplots are all used in a way that enriches and enhances the emotional power of the movie. The linkage of the Odones' story to various archetypical storylines create a "richer, far more complex text than a medical or journalistic account of Lorenzo's case would give." Ibid. As a compliment to the religious scenes of the film makes a strong statement that prayer alone will not bring relief to Lorenzo. The early religious scenes of the film give way to similarly shot scenes in the library. Religious music accompanies these scenes and other important moments, such as when Michaela finds the article on oleic acid in a Polish scientific journal and in the scene after the partial success of the Oil and the Odones, just before the testimonials when the camera pans to a ceiling of a church adorned with frescoes of angels. One analyst asserted that the film relies on three false myths of American culture. The first is that a cure can be found to any illness if only the bureaucracy and red tape will get out of the way. People want desperately to believe this. The second is a strong belief that perseverance, hard work and love can conquer any ailment. Third, is the theme that mainstream science is indifferent to the suffering of patients and their families. See comments of Dr. Arthur Caplan, then director of the Center for Biotechnics at the University of Minnesota, quoted in "Lorenzo's Oil: A Movie Outruns Science" New York Times, Feb 9, 1993, by Gina Kolata. The imagery, music,
lighting, and camera work in this movie are very direct in helping to build the emotion of each scene. We have already noted the music of the religious oriented scenes and the library scenes. There are at least two scenes in which the music is contrasted with a scene of normal life giving us a sense of great foreboding: (1) the scene of the party just before Lorenzo falls from his bike; and (2) Lorenzo's birthday party. In the scenes before the Odones receive the diagnosis, the camera sweeps through the family home and the neighborhood creating an imminent sense of danger. The same is true of the lighting, and while these techniques might appear heavy handed in other films, most audiences will accept them in this movie because the horror shown by the music, camera work, and lighting are more than matched by the horror of the Scenes in the film, the language used by the actors is Italian with English subtitles. Most of these scenes are very emotional. Putting the words in a beautiful foreign language with the translation in text on the screen insulates us from these emotions and, at the same time makes the scenes more poignant. They also make the scenes more memorable. We know that Mr. Odone is speaking from the depths of his heart when he lapses into Italian. The description of the disease and the path of the Odones in inventing Lorenzo's Oil are correctly laid out. Lorenzo was a bright boys who could speak several languages. His family had spent several years in the Comoros Islands. Augusto Odone (whose accent Nick Nolte imitated) worked for the world Bank, and Michaela Odone was a linguist. The characterizations of the personalities of Michaela and Augusto Odone, Deirdre, and Dr. Nikolais, appear to be reasonably accurate, at times exaggerated for dramatic effect. (Michaela's "mother tiger" qualities were overstated. She didn't slap her husband or kick her sister Deirdre out of the house. Note that these scenes were within the limits of poetic license and did not object. "Troubled Waters for 'Lorenzo's Oil'", Baltimore Sun, 1993: 26 Jan. D1, 3.) Lorenzo developed ALD, was treated at Johns Hopkins and in Boston, etc. Mrs. Odone's sister, Deirdre was a carrier for the ALD gene but did not have children at this time. She came to help the Odones and submitted to tests to see if the preparation of erucic acid would be harmful and if it would reduce levels of VLCSFAs in her blood. The side plots of with Omouri and Don Suddaby are primarily based on fact. Much of what is not factually accurate rings true in the literary sense. For example, Lorenzo was diagnosed with ALD. However, this was an important study and having Lorenzo participate allowed the study and the issues surrounding it to be presented in the film. Lorenzo was started on the Boston immunosuppression as quickly as possible. The rapidly progressive brain disease has inflammatory and autoimmune components. Immunosuppression was and still is, conceptually the best approach because dietary therapy effects take months to show themselves. Email from Dr. Hugo Moser, April 27, 2005. What appears to be one major flaw are the scenes in which the second child of Wendy Gimble, who had already started to exhibit neurological symptoms of ALD, got better when given Lorenzo's Oil. The fact that the oil stopped the progression of the disease in Lorenzo was an anomaly which scientists could not duplicate in other children who already had developed neurological symptoms. The film was not without its critics, chief among them Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly, Dr. Moser (Dr. Nikolais in the movie.) First and most importantly (Dr. Nikolais in the movie.) First and most importantly (Dr. Nikolais in the movie.) First and most importantly (Dr. Nikolais in the movie.) First and most importantly (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) First and most important (Dr. Nikolais in the movie.) Firs nearly as effective as portrayed in the film. He pointed to the irresponsibility of the movie makers when, without checking with the specialists in ALD, they claimed that Lorenzo's Oil worked on children who had already begun to develop symptoms. The boys who gave testimonials at the end of the movie could very well have been among the 65% of boys with the defective gene who don't develop symptoms until later in life. (Note that the clinical studies that led Dr. Moser, a careful scientist, always noted that "The crucial question as to whether timely administration of Lorenzo's Oil to asymptomatic boys with the biochemical defect of ALD can prevent the onset of neurological disability is still under investigation." It was only in 2002, almost ten years after the movie was released, that a study was completed that definitively proved that Lorenzo's Oil was very beneficial if treatment began before symptoms appeared Dr. Moser ran the study. If it had turned out that Lorenzo's Oil did not work consistently for any population, the film would be much less relevant today and would be much less relevan contributions that the Odones have made. The conceptual framework for the use of the monounsaturated oils, in particular, oleic acid, stems from the work of Dr. William Rizzo. [footnote omitted] The Odones clearly deserve credit for arranging the manufacture of the glycerol trioleate oil [oleic acid]. The most significant credit relates to their predicting that the use of glyceryl trierucate [erucic acid] would have a more powerful effect, for achieving its manufacture, and for testing it immediately in their own family." Quotations in the last two paragraphs from "Suspended Judgment: Reactions to the Motion Picture 'Lorenzo's Oil'", Hugo W. Moser, M.D., Controlled Clinical Trials 15:161-164 (1994). (See also "Lorenzo's Oil: A Movie Outruns Science" New York Times, Feb 9, 1993, by Gina Kolata.) Mr. Odone's account of his family's contribution to the development of Lorenzo's Oil. In October [1984] we organized an international symposium. One of the doctors said that giving patients oleic acid might reduce levels of the very long chain fatty acids. The reasoning, though I didn't know it at the time, was that such a substance might block the enzymes that synthesize very long chain fatty acids in the body.... I looked at animal experiments done over the past 50 years with different oils and decided to add a second ingredient called erucic acid [If you give Lorenzo's Oil to rats or mice their hearts clog up and they die.] That is where the dispute started. The dogma was that erucic acid was dangerous in people. A third objection voiced by Dr. Moser is that the movie implied a "conflict between objective therapeutic trials and the immediate needs of the patients. Such a conflict did not exist here .... The therapy was and is available to all families who wish to participate in the trials and virtually all do so...." Moser in "Suspended Judgment: Reactions to the Motion Picture 'Lorenzo's Oil'", citation above. He noted that approval of the open clinical trial took only 30 days. "Lorenzo's Oil" Film Review in The Lancet Vol. 341: Feb 27,1993 Mr Odone agrees that Dr. Moser was not accurately portrayed in the film, saying: "The movie was a little bit unfair to him.... He knows ALD inside and out, and he's a very compassionate person.... Dr. Moser's fourth important criticism referred to the "inaccurate and mean spirited representation of the parents' organization [the United Leukodystrophy Foundation]. The scene in which parents demand access to Lorenzo's Oil over the objections of the organization has had an important role in making the oil available to patients. The organization has also .." "Lorenzo's Oil" Film Review in The Lancet Vol. 341: Feb 27, 1993. (Dr. Moser also noted that "except that he wears a bow tie, [Peter Ustinov] has copied my appearance and speech with remarkable accuracy." "Lorenzo's Oil" Film Review in The Lancet Vol. 341: Feb 27, 1993.) Each of Dr. Moser's criticisms raise important concerns. As to Dr. Moser's third and fourth points, every film needs human villains. They are difficult to find in situations such as the fight against ALD when everyone is trying to do the right thing and there are many competing interests involved. "Lorenzo's Oil," on the whole, handles this conflict well. While Dr. Moser is unfairly treated, the audience cannot fail to see that he does what he can within the ethical restrictions of his profession. The characters of the Muscatines (the leaders of the parents' group)
are allowed to state their case, and it is a powerful argument. After Lorenzo's condition stabilized, the Odones established a non-profit foundation, The Myelin Project. The goals of the Myelin Project are to find ways to remyelinate nerves. However, because of the Odones' experience with the medical research establishment, the Myelin Project is a multinational gathering of families struck by one demyelinating disease or another. Refusing to accept the conventional view that science cannot be hurried, they resolved to advance the moment when myelin could be restored. They have done this by creating a framework in which researchers can cooperate effectively, by giving scientists adequate, prompt financing and by continuously interacting with them. ... To counter researchers' endemic conservative stance, we at The Myelin Project constantly remind them of two aphorisms: "fortune favors the brave," and "you never know until you try." The Myelin Project: An Overview. In June 2000, Michaela Odone died of lung cancer at the age of 60. Mr. Odone said that the constant care his wife provided to Lorenzo took a toll on her health. "It was her sacrifice for Lorenzo. She was with him 16 hours a day, continuously. We did not entertain people. We did not take vacations. It wore her out." (Los Angeles Times, June 12, 2000, page B4). See Obituary of Augusto Odone's paean to his late wife. Lorenzo lived until he was 30 years old, dying on May 30, 2008. Until his death, his mind was active, and he communicated by blinking his eyelids to say no and moving his fingers, the use of his fingers to say yes. He enjoyed music and being read to. Lorenzo never regained his sight, his speech, the ability to eat, the use of his fingers, the use of his fingers), or the use of his legs. When Lorenzo died, his father and his life-long friend Oumouri Hassane were at his side. He is survived by his father Augusto, his brother Francesco and his sister Cristina. Augusto Odone is writing a book about Lorenzo's story. The Myelin Project is still active. Click on the sections below to view discussion questions that may also be used as comprehension tests. For a printable version of this test suitable to distribute to a class (without suggested answers) click here. This test does not include questions about: (1) genetics (see Lesson Plan - Predicting Combinations for Alleles in a Zygote Using Punnett Squares); (2) the scientific method, see Lesson Plan - The Development of Lorenzo's Oil, Strange Twists of Fate, and the Scientific Method); and (3) the medical ethics of clinical trials (for a short quiz on that topic click here). 1. What does the term VLCSFA stand for? Suggested Response: A saturated fatty acid with a very long hydrocarbon tail. 2. Focus on a single link in the hydrocarbon tail of a VLCSFA. What are the elements that make up that link and how many atoms of each element are contained in each link? Suggested Response: The elements are hydrogen and carbon and one carbon and each link has two hydrogen atoms and one carbon atom. 3. What does the term VLCUFA stand for and how is it different than a VLCSFA? Draw a diagram showing the different linkages. Suggested Response: In VLCSFAs, the links in the hydrocarbon chain are made up of one carbon atoms in the chain. In an unsaturated fat, there is at least one link in the chain in the chain in the chain. In an unsaturated fat, there is at least one link in the chain in which one carbon atom fills the empty places in its valence shell by double bonding with the carbon atom in an adjacent link. The linkages are shown in the Diagrams of Four Fatty Acids. 4. What two parts of the body are most damaged by ALD? Suggested Response: The white matter of the brain consisting of the myelin sheaths that surround and insulate nerve fibers and the adrenal gland. 5. What are the two sources of VLCSFAs in the body? Suggested Response: VLCSFAs come from food and from biosynthesis by the body. Suggested Response: The smooth endoplasmic reticulum. This is a highly solution of the cell in which VLCSFAs are synthesized by the body. convoluted membrane within cells which is responsible for the biosynthesis of proteins and lipids. 7. What are peroxisomes and what is their role in maintaining safe levels of VLCSFAs in normal people? Suggested Response: Peroxisomes are microbodies (organelles) within cells that contain enzymes that oxidize various chemicals in the body, including proteins and lipids. Peroxisomes in liver cells keep the level of VLCSFAs at safe levels by oxidizing excess VLCSFAs. 8. What do normal people have that ALD patients do not have a transporter protein that moves excess VLCSFAs into the peroxisomes so that they can be degraded through oxidation. Peroxisomes in liver cells contain the enzyme that causes the oxidation of VLCSFAs. 9. Describe the model that Augusto Odone developed to show the problem of reducing VLCSFAs in Lorenzo's body. biosynthesis of VLCSFAs by the body. The drain represents the enzyme activity in the peroxisomes that oxidize VLCSFAs. The plug in the drain represents the failure of the body to transport the VLCSFAs to the peroxisome for destruction. In order to lower the water level (the level of VLCSFAs) both taps had to be turned off. See ALD and Lorenzo's Oil. 10. What was the contribution of the article by the Polish chemists and where did it leave the Odones? Suggested Response: The paper from the Polish chemists showed that when rats were fed oleic acid their blood levels of VLCSFAs went down. The next question was "why did this occur"? buildup of VLCSFAs in the body. Suggested Response: It inserts so many unsaturated fatty acids into the body that only a few VLCSFAs are made. 12. In the movie, the Odones were confronted with a number of questions that they had to answer. An early question was why Lorenzo's VLCSFA levels went up even when the VLCSFAs are made. from his diet. Hopefully, by looking at the sink model you know the answer. (It is that VLCSFAs were still being made by biosynthesis.) Another question the Odones had to answer was why biosynthesis of saturated fats was reduced when Lorenzo was given oleic acid, an unsaturated fat. Why did that occur? Suggested Response: Scientists had previously thought that the harmful VLCSFAs were produced by one enzyme added hydrocarbon chains to both saturated fatty acids and unsaturated fatty acids. If there were only a limited number of sites at which this enzyme was located, then as the amount of unsaturated fatty acids in the body increased, the opportunity for VLCSFA's? Suggested Response: No. It does not restore the myelin sheath. 14. When do symptoms of ALD appear and how many boys with the defective ALD gene will actually get the disease and show symptoms during that period? Suggested Response: Symptoms at ages 4 to 8, 15, Name five symptoms of ALD. Suggested Response: Symptoms include (1) poor memory; (2) loss of emotional control; (3) dementia; (4) muscle weakness; (5) difficulty in walking; (6) spasticity; (7) deficiencies with hearing; (8) problems with speech; (9) problems with speech; (9) problems with speech; (9) problems with speech; (1) difficulty in walking; (6) spasticity; (7) deficiencies with hearing; (8) problems with speech; (9) problems with speech; (9) problems with speech; (9) problems with speech; (1) difficulty in walking; (6) spasticity; (7) deficiencies with hearing; (8) problems with speech; (9) problems with speech; (1) difficulty in walking; (6) spasticity; (7) deficiencies with hearing; (8) problems with speech; (9) problems with speech; (9) problems with speech; (9) problems with speech; (9) problems with speech; (1) difficulty in walking; (6) spasticity; (7) deficiencies with hearing; (8) problems with speech; (9) problems with speech; (1) difficulty in walking; (6) specific with speech; (1) difficulty in walking; (6) specific with spech; (1) difficulty in walking; (1) difficulty in walking; (2) problems with spech; (3) difficulty in walking; (6) specific with spech; (1) difficulty in walking; (6) specific with spech; (1) difficulty in walking; (6) spech; (1) difficulty in walking; (6) spech; (1) difficulty in walking; (7) diff patients with untreated ALD? Suggested Response: Very poor. The disease, untreated, results in increasing disability and then death. 17. What is the earliest point at which ALD can be diagnosed with modern medical techniques? Suggested Response: Early during pregnancy. 18. Name two current treatments for ALD. Suggested Response: There are four: (1) Lorenzo's Oil (really a preventive treatment); (2) Adrenal steroid replacement therapy, (3) Bone marrow transplantation; and (4) symptomatic and support, and special education. 19. Are excessive levels of VLCSFAs part of the deterioration of the myelin sheath in ALD sufferers or is it a mere byproduct of that process? How do we know this? Suggested Response: An excessive level of VLCSFAs is part of the cause of the deterioration of the myelin sheath. We know this because when VLCSFAs is part of the cause of the deterioration of the myelin sheath. sheath. 20. What is adrenomyeloneuropathy (AMN), how does it relate to ALD, and who gets it? Suggested Response: It is the adult form of ALD. It is much milder than ALD and afflicts men between the ages of 21 and 35. 21. EXTRA CREDIT: The Odones were very lucky in their effort to find a way to arrest the progress of ALD in their son. One of the reasons that the scientists were reluctant to immediately publish the remarkable drop in the level of VLCSFAs in Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had no idea of what Lorenzo's blood was that they had
no idea of what Lorenzo's blood was that they had ingestion of Lorenzo's Oil. Suggested Response: There is no one right response to this question. Look for scenarios which are made could also make other compounds which are necessary for life. By crowding them all out with large amounts of unsaturated fatty acids, not only would the production of VLCSFAs be reduced but the production of these other necessary compounds could be reduced or eliminated. Lorenzo could have died or suffered a severe injury as a result. (2) The level of VLCUFAs could be reduced or eliminated. questions can be used as a test. Click here for a Microsoft Word version without answers.) 1. What risks did the Odones take by giving a combination of oleic acid and erucic acid to Lorenzo? Suggested Response: The risks were that the additional fatty acids would cause Lorenzo to have some other illness and that it would even make the ALD disease worse. Animals studies had shown the erucic acid caused heart disease in rats. Lorenzo's oil does have side effects. For example, it reduces platelet count.) However, the Odones thought that it was worth the risk because it was the only way that had any chance of reducing the level of VLCSFAs in Lorenzo's body. They were lucky. 2. What did the Odones gave a human being an untested therapy which had caused disease in laboratory animals without reviews and approvals by panels of physicians. See Medical Ethics. 3. What is a clinical trial? Why are there such strict rules regulating clinical trials? Suggested Response: A clinical trial is the testing of unproven treatments on human beings. The rules are strict because research scientists have a built-in conflict of interest between their personal interests in professional advancement and financial gain and the safety of their patients. While most researchers are ethical and would put the interests of the patient first, the lure of professional recognition or fortune could lead susceptible scientists astray. 4. What are anecdotal results and why are research doctors suspicious of them? Give an example of an anecdotal result from the movie. Suggested Response: Anecdotal results are observations of one or a few individuals. Researchers are suspicious of such information because it could be the result of unknown factors or an incorrect observation. Lorenzo's positive reaction to the Oil is a perfect example. The result was misleading because other children with ALD did not get better when they took Lorenzo's Oil. Except for Lorenzo's Oil works only on children who take it before they develop symptoms. 5. Why don't drug companies usually develop drugs for diseases like ALD? Do you fault them for this? Suggested Response: There is no one right answer to this guestion. A good answer would include the following concepts: Since so few people get ALD, there is no chance for the drug companies to make back the money they would have to invest some of those profits in research on the "orphan diseases." Then again, wouldn't a better use of their profits be to subsidize research on diseases that affect more people or AIDs treatment for people who can't otherwise afford it? 6. What was different about the Odone's situation that justified their willingness to take the risks despite the objections of the physicians? Suggested Response: ALD is invariably fatal in a short period of time, and the Odones had no conflict is between the interests of the doctor in professional recognition and financial gain. The Odones only had Lorenzo's interests at heart. 7. Why is ALD called an "orphan disease"? Suggested Response: ALD is an "orphan" disease because there are so few people with the disease that finding a cure was not a priority for the government, the drug companies, or the scientific community. In addition, there was no large organization of patients and their families to publicize the need for a cure or treatment. 8. What is the goal of the Myelin Project, the foundation started by the Odones? Suggested Response: To stimulate scientific research to find a way to remyelinate nerve cells. An alternative acceptable response would refer to the goal of The Myelin Project to provide a "framework in which researchers can cooperate effectively, by giving scientists adequate, prompt financing and by continuously interacting with them. ... To counter researchers' endemic conservative stance...." 9. Do you think that female carriers of ALD should have children? What about the boys who, because of Lorenzo's Oil and careful medical treatment, survive to adulthood and get married? Should they have children? Suggested Response: There is no one right answer. A good answer will refer to: (1) adoption as a good alternative; (2) the 50% chance with any carrier and with an having the genetic defect will have on a person's life. 10. Do you think that the leaders of the ALD society (Mr. and Mrs. Muscatine) as portrayed in the movie acted in the way that leaders of a support group should act? Suggested Response: First, note that Dr. Moser contends that the parent's support group (The American Leukodystrophy Association), were helpful and that the scene of the meeting in which the parents demanded access to Lorenzo's Oil never occurred. This question portrayed in the film. There is no one correct answer. A good answer will note the following concepts: Leaders of citizen groups interested in helping families with diseases such as ALD have a multi-faceted role. They are advocates for their members, the victims of the disease and their families. They also help their members, the victims of the disease and their families. the best thing to do is to follow the doctors' advice and follow standard procedures. Depending upon their beliefs, some families may think that it is better to let the afflicted child escape his misery. In this case it wasn't, but that was because of unusual luck and the perseverance of the Odones and Dr. Moser, 1. Describe two scenes in which a sense of foreboding in the music is contrasted with a scene of normal life. Suggested Response: (1) The scene just before Lorenzo falls from his bike and (2) Lorenzo's birthday party. 2. Name two archetypal storylines which are used to add depth to the film. Suggested Response: Here are three: (1) The Christ story of someone who suffers for the benefit of others; (2) The struggle of people against a heartless nature; (3) the struggle of powerless people against a heartless nature; (2) images of Lorenzo is associated with the Christ child. Suggested Response: Here are four. There are several more. (1) the religious sounding music; (2) images of Lorenzo and his mother are contrasted with a statue of the Madonna and Child; (3) the scene in which Augusto Odone asks his wife "Do you ever think that maybe all this trouble has been for somebody else's kid?"; (4) the scene near the end of the film, just before the testimonials, which shows a ceiling of a church with frescoes of angels. 4. Name two myths of American culture that are fostered by this film. Suggested Response: There are three. The first is that a cure can be found for any illness if only the bureaucracy and red tape will get out of the way. People want desperately to believe this. The second is a strong belief that perseverance, hard work and love can conquer any ailment. In fact this is not true, as is demonstrated by the many people who have exhausted themselves and compromised their health by caring for an injured child or loved one. The third is the themselves and compromised their health by caring for an injured child or loved one. director use this device? Suggested Response: Putting the words in a beautiful foreign language with the translation in text on the screen insulates us from these emotions and make it easier to dealt with them. The Italian makes the screen insulates us from these emotions and make it easier to dealt with the translation in text on the screen insulates us from the screen insulates us from the depths of his heart when he lapses into Italian. 1. Think of the theme of the film that relates to a man battling a harsh and uncaring natural world. What is ironic about this theme in its application to the experience of Lorenzo and Michaela Odone? Suggested Response: The agent of the harsh and uncaring nature was their own genes. 2. Do you think that the Odones were arrogant as the head of the Foundation claimed? Suggested Response: There is no one right answer to this question. A good answer would include the concept that any amazing
accomplishment can be said to be arrogant. 3. What was the role of luck in the Odones' search for a way to stop the deterioration of Lorenzo's condition? Suggested Response: Phenomenal. They were very lucky to have found two oils that helped some children with ALD and that did not have devastating side effects. They were lucky that the Oil had any positive effect on Lorenzo, when it didn't help other children with ALD and that did not have devastating side effects. communicate with each other? Suggested Response: Opportunities for putting different ideas together and finding a good result are lost. 5. What does this movie demonstrate about the role of scientific symposia in the process of advancing scientific knowledge? conversations and seminars that can lead to scientific breakthroughs. The government and foundations supporting scientific research spend hundreds of thousands of dollars on symposia each year, paying scientific research spend hundreds of thousands of dollars on symposia each year. symposium to the Odones. 6. What is "modeling" in scientific research and how does it help scientists make new discoveries? Suggested Response: It provides a way to visualize a problem or a natural phenomenon so that scientists can focus on a solution and come up with new ideas about hypotheses to test. 1. Compare the reaction of this family to the other families with children who had the same illness. Could every family have reacted in the way that the Odones did? Suggested Response: The Odones had a particular combination of intelligence, drive, and independence which caused them to look on their own for a therapy. In addition, the library of the National Institutes of Health was within driving distance from their home. The Odones didn't stand in awe of the doctors as other ALD parents did. 2. Were there any special attributes that the Odone family possessed which permitted them to find a way to stop the deterioration of their son's health? money to the effort of finding a cure. 3. Should Michaela have felt guilty that it was her genes that contained the defect that caused Lorenzo to have ALD? Suggested Response: No. She had no control over it. The disease was only first described ten years before, and no one had warned her that she needed genetic counseling. ILLNESS -DISABILITIES 4. Before the discovery of Lorenzo's Oil, was it better to simply allow children with the ALD defect to die? Suggested Response: This is a highly emotionally charged question, and for some, it raises important religious issues. The main point is that no matter how strongly people feel about it in their own lives and based on their own

religions, reasonable and ethical minds will disagree. There is no one right answer to this question. Good answers will deal with some of the following issues of the ethics of giving up on a life: the fact that if the Odones hadn't tried so hard, Lorenzo's Oil would never have been invented; the trade-off of resources spent on helping the few children suffering from ALD could be better used helping thousands (or more) children suffering from less complicated diseases or starving); the cost to the Odones' lives of their single-minded devotion to Lorenzo; and the quality of Lorenzo is life. 5. Michaela Odone devoted herself to caring for Lorenzo and gave up most other parts of her life. She exhausted herself in caring for him. Her husband believes that it hastened her death. Do you think that she reacted in the right way to her son's illness? What would you have done? Suggested Response: There is no one right answer to this question. A good answer will discuss the issues raised in the answer to the preceding question and note that people all over the world exhaust themselves caring for a sick loved one. 6. What did you think about Dr. Nikolais? Was he a good doctor or not? Suggested Response: Dr. Nikolais is depicted as a caring physician who is unwilling to go outside of the ethical rules of his profession to save Lorenzo's life. Note that even though he won't participate in the erucic acid trial on Lorenzo he gives advice to Mr. Odone as to the dosage. Dr. Nikolais is used in the film to represent the medical research establishment and a major theme of the film is the difficulty that medical research establishment and valid reasons to protect the human subjects of clinical research. SISTERS 7. Describe the relationship between Michaela Odone and her sister. Suggested Response: Deirdre was a caring sister who only wanted to help. Michaela's anger at her was part of Michaela's anger at her was par he had a mind. Michaela's faith, it turns out, was justified. Discussion Questions Relating to Ethical Issues will facilitate the use of this film to teach ethical principles and critical viewing. Additional questions are set out below. RESPONSIBILITY (Do what you are supposed to do; Persevere: keep on trying!; Always do your best; Use self-control; Be self-disciplined; Think before you act — consider the consequences; Be accountable for your choices) 1. The movie starts with the following passage on the screen: Life has meaning only in the struggle. Triumph or defeat is in the hands of the Gods . . . So let us celebrate the struggle! — Swahili Warrior Song. What are the filmmakers trying to tell us by putting this guote at the beginning of the movie? Suggested Response: There is no one right answer to this guestion. A good answer will demonstrate sober reflection. Samples of two good answers are: (1) the experience of the Odone family ennobled them despite the fact that Lorenzo is still disabled; and (2) it means that it is how you live your life that gives it meaning, not how successful you may be. 2. Is there a difference between fulfilling a responsibility (doing what you are supposed to do, persevering, and always doing your best) and what the Odones did for Lorenzo? Suggested Response: The Odones could have done a lot less for Lorenzo and still have complied with the duties imposed on them by their love for Lorenzo and by their ethical responsibilities. See questions in Illness-Disabilities section above. CARING (Be kind; Be compassionate and show you care; Express gratitude; Forgive others; Help people in need) 3. Does everyone need people to help them out at certain times? Where would Lorenzo be without those who cared for him? Where would you be if, in your times of need, people had not helped you out? Suggested Response: Everyone needs help at many points in their lives. 1. A class which is enthusiastic about this film can hold a bake sale or a car wash and donate the proceeds to The Myelin Foundation. 2. The class can write a letter to Lorenzo, individually or as groups. The teacher can review the letters and send the best to Lorenzo c/o The Myelin Project, 2136 Gallows Road, Suite E, Dunn Loring, Virginia 22027. 3. Assignments, Projects, and Activities for Use With Any Film that is a Work of Fiction. The links and articles referred to in the Guide. ACKNOWLEDGMENTS AND THANKS: To Imelda DeVera for her tireless work on this Learning Guide and the lesson plans that accompany it. This Learning Guide was last updated on December 10, 2009.

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