

Lorenzo's Oil Viewing Guide

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, *Lorenzo's Oil*

At century's end, the relationship between medicine and the movies, like that between medicine and the lay public it serves, has become far more complex. If anything, popular movies now have greater influence on public attitudes and behavior, even on public policy, than they did earlier in the century. They can create problems for physicians in many ways—some as straightforward as misinforming patients about the efficacy of specific medications, some as subtle as undermining patients' trust in the entire enterprise of medical research.

What have you learned about ALD (Lorenzo's condition)? Is there a cure/treatment? Have other kids been cured/treated? What do you think about the doctors? What about the support group?

You hear many claims made every day. Advertisers make claims about the usefulness or effectiveness (efficacy) of their products. Your friend may claim to be able to do something that you do not think he or she can really do. Do you believe all the claims that people make? When does a claim become a *fact*? Scientists look for evidence to support or refute a claim. Evidence can help you determine which claims are facts and which are opinions or even misrepresentations.

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.

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. Other sciences such as biology or anthropology may also use observation and description.

List the steps of the scientific method.

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 Odone's do not accept this verdict and embark on a dramatic search for a way to save their son. Viewing this movie provides a mental exercise in applying the scientific method and developing hypotheses in an interesting real world situation. The movie builds interest by pointing out that despite the Odone's hope that they have found a therapy for ALD and the claims made in the movie, the effect of Lorenzo's Oil on Lorenzo was an *anomaly*, (deviation or departure from the normal or common order, form, or rule.) Furthermore, it was only by luck and perseverance that the oil was found to be helpful to boys who were quite different than Lorenzo.

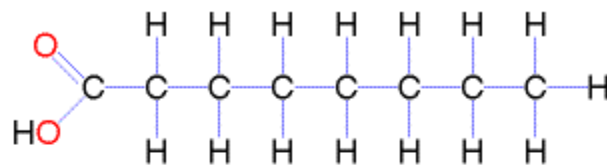
As a factual documentary the movie has three main flaws: it overstates the success that can be achieved with the oil, it invents conflicts between the parents and the medical establishment, and it presents an inaccurate and malicious

portrayal of a valued parents' organization [the United Leukodystrophy Foundation]". The real doctor also objected to the film's depiction of Lorenzo's enrollment in a trial that restricted dietary VLCFAs, because that trial had ended in 1982, before Lorenzo became his patient.

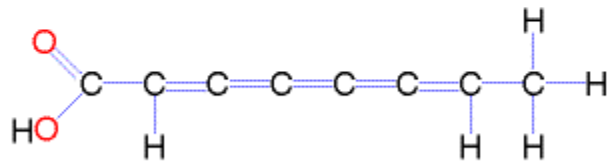
Is this movie 100% fact?

What is Adrenoleukodystrophy?

Adrenoleukodystrophy (ALD) is one of a group of genetic disorders called the *leukodystrophies* that cause damage to the myelin sheath, an insulating membrane that surrounds nerve cells in the brain. People with ALD accumulate high levels of saturated, very long chain fatty acids (VLCFA) in the brain and



Saturated



Unsaturated

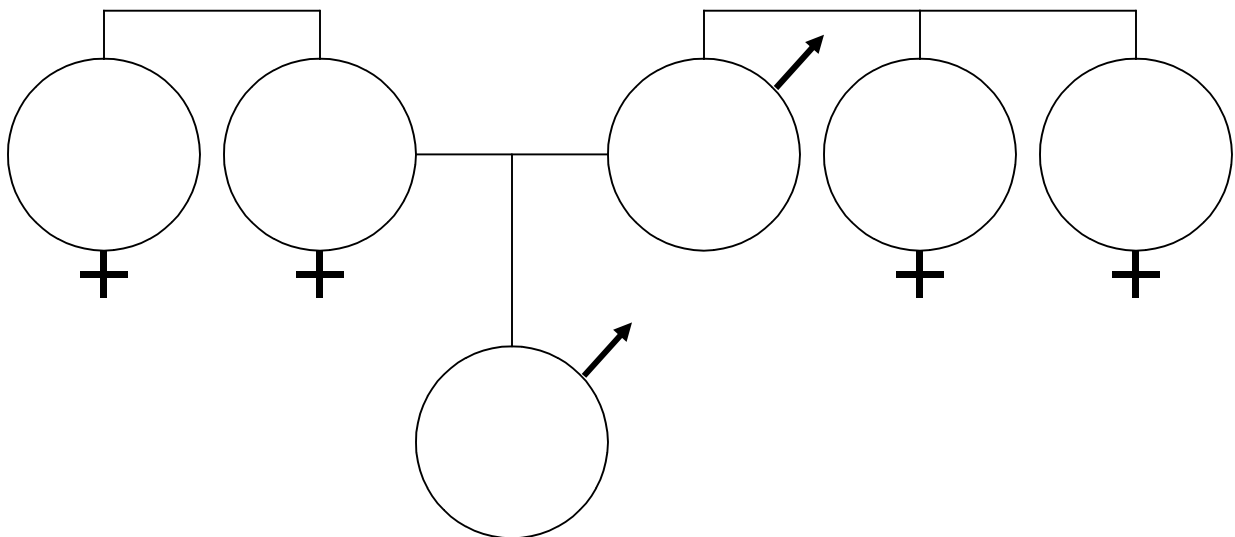
adrenal cortex because they do not produce the enzyme that breaks down these fatty acids in the normal manner. The loss of myelin and the progressive dysfunction of the adrenal gland are the primary characteristics of ALD.

ALD has two subtypes. The most common is the **X-linked form (X-ALD)**, which involves an abnormal gene located on the X-chromosome. Women have two X-chromosomes and are the carriers of the disease, but since men only have one X-chromosome and lack the protective effect of the extra X-chromosome, they are more severely affected.

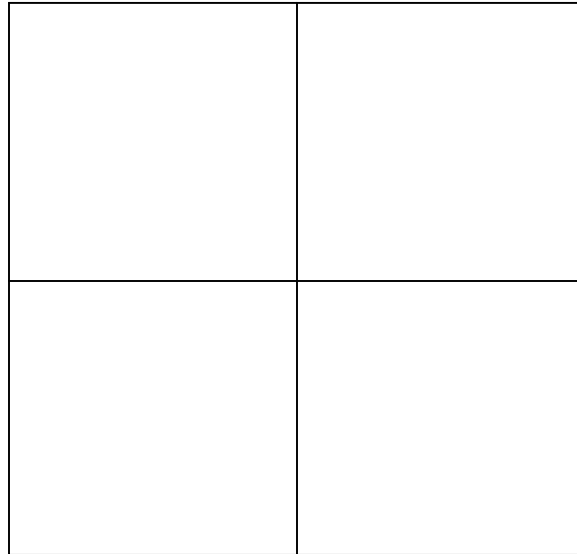
1. Lorenzo's parents used the scientific method to solve their problem. State the problem, ask a question and use examples from the film to illustrate the steps.

2. From the description of the disease, ALD, sketch what Lorenzo's neurons most likely looked like after a year. Include a sketch of a normal neuron.

3. ALD is a recessive sex-linked or X-linked disease. What are the probable genotypes of the family members listed? Aunt #1, Aunt #2, Aunt Dee, Michalla, Augusto, Lorenzo.



4. Draw a Punnet square representing Michalla and Augusto. What percentage of the children could have the disease? _____ What percentage could be carriers? _____ What percentage of the boys would have the disease? _____ What percentage of the girls would have the disease? _____



5. From which parent did Lorenzo inherit the disease?

6. What is Lorenzo's Oil?

7. How does it work? Use the sink model from the film.

8. Why did the medical community resist the Odone's treatment ideas? Why did the parent support group resist? Give examples of arguments for and against.

9. The definition of analogy is: Similarity in some respects between things that are otherwise dissimilar. A comparison based on such similarity.

How do analogies help you to understand the scientific problem?

How did modeling help solve the scientific problem?

Can you think of other great discoveries that employed the use of models?

10. Did the family's courage and persistence inspire you? How.

11. How did Augusto and Michalla demonstrate "life-long" learning?

12. Diseases that affect a small % of the population often do not get as much money for research as the big killers like cancer and heart disease. Do you agree or disagree with this? Explain why.

13. What was found out from the Polish biochemist? What was the purpose of the ALD Symposiums? What happens when scientists work in isolation? Why is the research component of the scientific method so critical?

14. What are the common names for erucic acid and oleic acid?

15. The treatment for ALD really happen by accident? (Eureka:Used to express triumph upon finding or discovering something. *I have found (it) (supposedly exclaimed by Archimedes upon discovering how to measure the volume of an irregular solid and thereby determine the purity of a gold object.)* Can you think of any other times in medical history where an important discovery happened by mere chance?

16. As a class, debate the bioethical issues regarding research time and money spent on rare genetic disorders as compared with common diseases.

“This is a true story although certain characters and incidents are fictional.” Even those attentive few who do see the notice have no way of knowing which are the fictional characters and incidents.