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## **A Clarion Call for Health Independence**

**by Wendy McElroy**

*Lorenzo's Oil* (1992) is one of the best movies you've never seen. This incredible drama hit the big screen for two seconds before skidding into rental stores, where it failed to find the wider audience it deserves.

*Lorenzo's Oil* is a compelling reality-based story of parental devotion and the triumph of truth over authority. It is a beautifully acted and skillfully directed tribute to the power of love to prevail, it seems, over death itself.

The movie opens in 1983. Augusto (Nick Nolte) and Michaela (Susan Sarandon) Odone watch in horror as their only son, Lorenzo, rapidly degenerates from a disease so rare that no one is pursuing a cure. Indeed, at first, no one knows what is happening to the five-year-old.

Lorenzo is ultimately diagnosed with adrenoleukodystrophy. ALD is an inherited, sex-specific genetic disorder passed from mother to son in which the myelin sheaths — the fatty coverings that surround and protect nerve cells in the brain — deteriorate, resulting in physical and mental breakdown. (As a disease, it is related to multiple sclerosis.) In more practical terms, the breakdown means that Lorenzo dissolves from being a precocious and delightful child into a violently disturbed boy who is finally unable to perform simple biological functions such as swallowing.

The boy is going to die and soon; that is the consensus of every doctor and scientist whom the Odones consult. Lorenzo is going to live; that is the quest of his parents. They have no medical or scientific training. Augusto is an Italian economist; Michaela is an Irish-American linguist. Nevertheless, as Augusto states, "When you are in a strange country, you learn the language."

At first, the Odones speak the language (medicine) in a conventional manner. Because ALD is both a newly discovered disease and a rare one, there is little hard data or funding available. At first, they accept the experimental treatments, the need for control-group research, and other standard slow-moving approaches. But Lorenzo does not have the luxury of time.

Soon the Odones are ransacking medical libraries and pursuing every footnote on human or animal research that bears even remotely upon ALD. They pursue information from doctors and researchers with a passion commonly associated with stalkers. Eventually, the Odones organize an international symposium to discuss ALD. A division of labor emerges through which Augusto becomes the primary researcher and Michaela the caregiver, but each participates equally in the crusade to save Lorenzo.

Many doctors are hostile, not helpful. Clearly, they are annoyed and offended by aggressive lay people who do not accept their authority but, instead, have the audacity to seek a cure. Even some members of a support group for parents of ALD boys condemn the Odones for not facing the reality of their son's impending death.

Alone and racing against death, the Odones persist for three years before finding the clue that leads them not to a cure but to a treatment; oleic acid can destroy the fatty acids that are destroying Lorenzo's brain. Augusto develops a formula he calls "Lorenzo's Oil" — a combination of two fats extracted from olive oil and rapeseed oil. The formula proves remarkably effective in presymptomatic boys with the ALD gene because of its ability to halt the body's production of the specific acids that attack the myelin sheaths.

Dr. Hugo Moser, the world's foremost authority on ALD, subsequently conducted a 10-year study in which 120 presymptomatic boys with the gene for ALD were given Lorenzo's Oil. Eighty-three of them remained disease-free. From the data, Moser concluded Lorenzo's Oil reduced the onset of disease by half. Augusto later received an honorary Ph.D. for his work.

For Lorenzo himself, however, the discovery came too late. The treatment could not repair the extensive damage to his brain. The real life Augusto shifted his attention to research on the regeneration of brain tissue. The movie ends with a 12-year-old Lorenzo who has improved significantly enough to be able to communicate through sign language.

Today, Lorenzo is 28 years old. Although he has little body function, his mind is alert and he is reported to enjoy music and listening to books.

Several factors combine to make *Lorenzo's Oil* a superb film.

The acting is exquisite. Saradon, of whom I am generally not a fan, received a well-deserved Oscar nomination for her role.

The director and co-author, George Miller, whose credits include *Mad Max* and *The Witches of Eastwick*, produces a near-flawless movie that is brilliantly edited. He also provides a fine emotional balance. A medical doctor himself, Miller does not demonize the experts who obstruct the Odones' quest. He condemns the mechanistic approach now prevalent in medicine without condemning the people who employ it. To this end, Peter Ustinov is perfectly cast as a sympathetic, well-meaning doctor who simply cannot help as long as he stays within protocol. Miller's background also imbues the movie with a medical accuracy that is disturbing and

difficult to watch but never gratuitously so. You hate to see Lorenzo suffer but his suffering, after all, is the crux of the film.

The movie's themes are haunting. Perhaps the most obvious one is the power of parental love. This theme is best captured by Sarandon's fierce portrayal of Michaela, which reveals a maternal devotion that is literally frightening in its intensity.

The power of marriage is an equally strong theme. It is inconceivable that the Odone could have endured Lorenzo's illness, their financial difficulties, and the scorn of the world without having each other. Especially today when marriage (or partnership) is often viewed as disposable, it is heartening to view a family who will never abandon or give up on itself.

On a more political level, the overriding theme is "Question Authority." Early in *Lorenzo's Oil*, Augusto requests medical material to better understand what is happening to his son. Without meaning offense, a doctor assures Augusto that he could not make possibly make sense of the studies. The Odone do not stop questioning even when the responses are openly hostile. Their willingness to tolerate both unlikely theories and the skepticism those theories elicit is precisely what leads them to the source of an effective treatment: olive oil. It is not merely that experts are shown to be fallible and constrained by narrow thinking. It is that ordinary people are shown to be capable of realizing their own self-interest even in "expert only" areas.

Finally, *Lorenzo's Oil* is a counterargument to the assumed need for government funding and law to regulate all things medical in order to ensure progress and quality care. The movie is a clarion call for individuals to take control of their own bodies and their own medical well being. It is the triumph of personal responsibility over bureaucracy, the individual over the system.

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