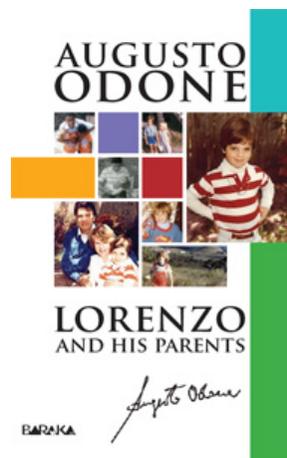


LORENZO AND HIS PARENTS - INTERVISTA AD AUGUSTO ODOE

La casa editrice [Baraka](#) pubblica in inglese la storia di Lorenzo Odone, affetto da una rara malattia genetica. Ce ne parla l'autore, Augusto Odone, padre di Lorenzo.



Lorenzo's Odone has been struck by a little studied rare genetic disease. His story has become a book in 2010. Previously, Lorenzo's story had inspired a movie directed by George Miller and interpreted by Nick Nolte and Susan Sarandon. The book written by Lorenzo's father has recently been published in English by Baraka, in order to spread Lorenzo's story internationally and give hope to sufferers of so many diseases struck by little known pathologies. The book can be purchased following this link: barakanet.com. Proceeds of the sales will be donated to researchers. We have interviewed Mr. Odone to better know Lorenzo's story and purposes and ideas that have inspired the book.

The story you told is painful but also full of hope: a little boy, an unknown disease, a father who does not give up. What was Lorenzo's disease?

Lorenzo's disease was Adrenoleukodistrophy (ALD), a disease that strikes little boys between 3 and 7 years old.

ALD is a genetic disease and women are usually healthy carriers. The effects are that after terrible pains children die before they reach ten years of age. Lorenzo was diagnosed with ALD when he was six in 1984 but our story has started before. My wife Michaela was reading a story when Lorenzo said I cannot hear you. Michaela called me -- I was at work - I came back at home and noticed that indeed Lorenzo could not hear. We went to an otorinoringoiatra specialist who told us that there was nothing wrong with his ears and that the problem was probably neurologic. We then went to doctor Fishman. He gave us almost by chance the right diagnosis. ALD is very rare and he could identify it since, as he later told me, because he had recently read an article on the subject. Together with the diagnosis we received a terrible blow. Dr. Fishman told us that there was no remedy and that Lorenzo would die within 2-3 years.

How did you react to this news?

At first, we did not believe this grim diagnosis. We wished to have a second opinion. Dr. Moser, the world specialist on ALD confirmed Dr. Fishman diagnosis. We also did some blood analyses which showed my wife to be a healthy carrier. Since that moment we started to believe that indeed our son had ALD. We began to frequent Washington libraries and to consult the index medicus on all articles which dealt with Lorenzo's disease. We took turns and in the evening we exchanged the information we got during the day. With the help of Hugo Moser, who was to become a very good friend of mine, our research led to the discovery of Lorenzo's Oil. Lorenzo died when he was 30 years old not because of ALD, but because he had ingested some food that provoked a mortal infection.

Would you mind to tell us your relation with traditional medicine and alternative medicine?

What I wish to say is that Lorenzo's Oil is a scientific endeavor. It treats a very specific disease but not all.

Why did you think of writing a book on Lorenzo's Oil?

Because Lorenzo would continue to live.

In this connection what can be done to cope with situations similar to that of Lorenzo and anyway with little known, rare diseases?

The book has an inspirational aspect: I hope that readers may follow me and my wife example and above all that the book will help them to feel less isolated. One of the recommendations of my book is that people should always ask for a second opinion particularly in the case they are afflicted by a rare disease. As far as possible the second opinion should be sought from a specialist. In other words we can't rely only on the local doctor.

Why did you think of translating your book in English?

The story I recount is for everyone but it develops within an Anglo-Saxon context. It is from that context that the first requests of my book have come from. This translation will serve to answer a wish of diffusion coming from people I personally know or I think I do. I hope that many readers will appreciate my endeavor because has nothing paternalistic. It wish to be a little gift and a little, great remembrance.

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12 Gennaio 2013

Cultura e pedagogia

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