



SCRIPTS

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Lorenzo's Oil

By George Miller

- One orange.
- One orange.
- Chungwa moja.
- Chungwa moja.
- Two oranges.
- Two oranges.
- Machungwa mawili.
- Machungwa mawili.
- One pineapple.
- One pineapple.

Omouri! Omouri!

Here he is,

the cleverest boy in the world.

- Hi, Mom.
- What's this?
- It's a picture.
- Oh, my goodness.
- And there's the Comoros.
- Of course it is.
- Mrs Odone, may I have a word?
- Very skilful, sweetheart.
- And Jupiter.
- Jupiter next to the Comoros?
- I'll be right there, Lorenzo.
- OK, Mommy.
- Is Lorenzo having problems at home?
- Not that I know of. Why?

Today he started throwing paints around.

He went wild, destroying other paintings.

- He must have been provoked.
- No, it came out of the blue.

He's normally such a terrific kid.

- Darling, were they teasing you?
- No.
- Were they touching your paints?
- No.
- How were they annoying you?
- They just were.
- Doing what?
- Things.
- What kind of things?
- Things that make me feel annoyed.
- Mrs Odone...
- Another incident?

Yes, and today it was much worse.
Mrs Odone, is there
some trouble at home?
Why do you assume
the trouble's at home?
Because there's nothing here that
explains his behaviour. It's... disturbed.
He does present as a hyperactive.
- But don't they repeat tasks endlessly?
- They persevere, yes.
Lorenzo's activities all have a structure:
beginning, middle and end.
My gosh, he's learned three languages.
How could he be hyperactive?
I know it's hard to accept that
a gifted child may also be disturbed.
Lorenzo needs to be
referred to an IDP committee.
- What's that?
- For what?
Individual Disability Placement.
Lorenzo needs to be
in a special ed class.
Any special ed our son needs
will be provided at home.
Anyhow, it was snowing and he began
to rub my hands to warm them.
Uh-oh.
No, he then produced photos
of his wife and children.
- That old routine!
- Oh, Deirdre!
Had I known this was the man
I would wait ten years for...
- ...I'd have let you pick up the cheque.
- I did.
Excuse me! You did not!
Lorenzo's fallen off his bike
and he is really bleeding.
Sh. That's a boy.
Oh, such a brave boy.
Doing just fine, here.
You're going to be OK.
It's Christmas Day, you know.

All across the country
little boys are trying out their new bikes.
Hey, champ. I think you'd better
tell your folks to lighten up.
What are they gonna do when
you're playing for the Redskins?
The EEG is normal, the skull x-ray
is normal and the CT scan is normal.
I don't know what to tell you.
This boy is neurologically intact.
Doctor, we spent
three years in East Africa.
- In the Comoros.
- We were wondering...
Well, if he might have
picked up some rare parasite.
It's possible.
Lorenzo, what are you doing?
Lorenzo!
Sweetie? Can you hear Mommy?
This may be an auditory
processing difficulty.
The ears hear all right,
but the brain has trouble listening.
So, this means something
is affecting his brain.
But what? A tumour? Multiple sclerosis?
It could be any one of a dozen things.
Listen, my friend. I'd like you to come
and stay in the hospital for three days.
Your mom and dad can come too.
We're gonna run some tests
and get to the bottom of this.
Can you hear the sound?
Keep your eyes right on that spot
for me. That helps me out.
All right. Now close your eyes.
Keep your eyes closed, buddy.
Stay nice and still.
Of course, Easter festivals
existed long before baby Jesus.
In pagan times, they marked
the beginning of Spring.
The egg tells us that the earth is going to

be reborn, just like a little baby chick.

- I get it.

- Mrs Odone. Mr Odone.

Dr Judalon is ready now.

Hey, Lorenzo, would you like

to go feed the goldfish?

It's all right, sweetheart. Go ahead.

We'll be right back

in just a few minutes. Go ahead.

This way, please.

Please, have a seat.

Well, we certainly don't need

that noise, do we?

So...

Please, Doctor, without equivocation.

There is a family of diseases.

It's quite rare.

The leukodystrophies.

Lorenzo has one of them.

It's called ALD.

ALD is an inborn error of metabolism

that causes a degeneration of the brain.

It only affects males, usually

between the ages of five and ten.

Its progress is relentless.

The end is inevitable.

All boys with ALD die, usually

within two years of diagnosis.

And there are no exceptions?

I am so sorry.

- Are you absolutely sure?

- Yes.

Lorenzo shows the definitive sign:

...an abnormally high level of fat in his

blood, certain long-chain saturated fats.

Oh.

Uh...

These fats... destroy his brain?

But how?

There is an enzyme

that should metabolise these fats...

...but in ALD boys it's defective.

So they collect in the nerve cells, a

little bit like a cluster on the arteries.

And... in some way...
...this liquefies
the white matter of the brain.
"Some way liquefies"?
Could you be more specific?
Well, to be honest, we're not
quite certain just how it works.
- You know what myelin is?
- No.
Myelin is the fatty... sheath
that insulates the nerves.
It's a little bit like plastic
around electrical wires.
Without it, the nerves
cannot conduct an impulse.
What ALD does is strip away the myelin.
It corrodes it, if you like.
This causes degeneration of the brain
and the body loses its functions.
But surely someone, somewhere,
must be working on this, no?
- We would go anywhere.
- Yes.
Ten years ago the disease
hadn't even been identified.
We're still trying to
understand just what it is.
I would like to
offer you some hope, but...
Then there's absolutely no treatment?
Normally at this point
we try to be constructive.
We try to focus on what can be done.
But in this case...
When we get home, can we read a story?
Of course, my darling.
Lorenzino, let's go home.
Mr Odone? I have
a Dr Judalon on line three.
- Good. Put him through.
- They're waiting for you in the meeting.
All right, thank you.
- Hello?
- Augusto?

I just got off the phone
to Gus Nikolais...
...a professor of neurology at
the Institute of Childhood Diseases.
If there is a so-called "world expert"
on the leukodystrophies, Nikolais is it.
- Ah, good.
- I don't want to raise false hopes...
...but he's working on
an experimental protocol based on a diet.
Wonderful.
Peanut butter, red meat, cheese...
Unpeeled fruit, spinach, olive oil...
But these are healthy foods.
Yes, but they contain
very long-chain saturated fats.
I...
I still do not understand why
they are so harmful to Lorenzo.
- Why are they so destructive?
- How can spinach make the difference?
The human body needs these fats
in order to create cells...
...and the excess is burned off.
That's normally, of course.
But in the case of an ALD boy,
these saturates can't be broken down...
...and they build up in the brain.
And somehow this build-up
strips the myelin covering.
Yes, exactly. And, for the moment,
we don't know why this is.
But we feel that, by withdrawing
the saturated fats from the diet...
...we will prevent them
accumulating in the brain.
And if we could?
There's no way to reverse
neurological damage.
All we can hope for is
to slow the cascade of symptoms.
But if it's any consolation to you,
you'll be helping us...
...understand the biochemistry

of this heartless disease.
So, can we enrol Lorenzo in our trial?
I suppose so.
Good. Then I will pass you
over to our dietician...
...and meanwhile we should arrange
some genetic counselling.
Oh, Dr Nikolais, it's highly unlikely
that we will have another child.
No, but your sisters and their daughters
may all be carriers.
- We need to test them.
- Only my family? What about his?
No, no. ALD is passed
only through the mother.
But I thought you understood all this.
We knew it was inborn, but...
...we assumed that meant
a combination of our genes.
That's true in other inherited diseases...
...but ALD is only carried
on the female chromosome.
Excuse me.
Are you saying that Lorenzo
got this directly from me?
Well, in the sense that
ALD is sex-linked, yes.
It goes from mother to son.
- And how did I get it?
- The woman gets it from her mother.
And if I inherited the defect,
why don't I have the disease?
No, the woman is only
the carrier, nothing else.
But with each conception, she has
a 50-50 chance of passing on the defect.
And when that happens...
It's the cruellest kind of genetic lottery.
- Lottery?
- Yes, a clumsy word.
I use it because it's...
so arbitrary, you know.
- No one is to blame.
- Um...

If Michaela's mother had this...
...and her mother's mother...
...why was there no warning?
Well, I suppose if you went back
into the family tree, you'd...
But remember, a short time ago
this disease didn't even have a name.
Mrs Odone, you have enough
to put up with without...
You have nothing to blame yourself for.
Thank you.
It's not a good idea.
All right, so she doesn't want me. What
about Mother? She's packed and ready.
Kenise, Michaela doesn't
want anybody around.
What about Father Killian? He can come.
Hell, no. She's not even
going to Mass now.
- Deirdre, what is happening there?
- Just let it rest, OK?
No. What will they do
for Lorenzo's birthday?
- I'll call you. Bye.
- No. Deirdre!
This is wrong. More than ever
she needs her family here.
She doesn't want nobody.
She's too angry.
We cannot afford the time to be angry.
Come on, look what she's dealing with.
She does not have to deal with it alone.
She feels incredibly alone and unlucky,
like she's been singled out by God.
- Oh, Deirdre!
- Yes! Kenise is a carrier with two girls.
Me, a carrier with no kids at all, and
Mariah has a boy but she's not a carrier.
So only Michaela gets this laid on her.
- This did not happen only to Michaela.
- Sure. You got two kids already, Odone.
Mommy will make you something better:
...a big-boy fruit treat
with five different colours.

She waited all this time to have one child. She's not gonna have another.

Francesco! Cristina!

- Ah, buongiorno.

- Oh, Francesco!

- Cristina.

- Michaela.

Ciao.

Everyone, this is Lorenzo's sister and brother, all the way from Rome.

This does not make sense.

Lorenzo's saturated fats have risen.

We eliminate them from his diet, and in his blood they increase.

If these very long-chain saturated fats are destroying his mind...

...then surely we should take him off the diet.

Mr Odone, please be patient.

Your son has been on the diet only six weeks. Wait until the end of the trial.

Dr Nikolais, what about the other boys?

What results are you seeing in them?

As with Lorenzo, it's too early to tell.

We need the study to run for the full six months.

That will tell you what is obvious right now...

...that avoiding apple skins and pizza has no effect on this brutal disease.

Now, please, Doctor, is there anyone out there who is chasing a definitive therapy?

You judge us too hastily. The French have tried bone-marrow transplants...

...and in Boston we're about to try immunosuppression.

- Why haven't we heard of these before?

- The transplants were disastrous...

...and the immunosuppression is highly experimental.

The protocol has been limited to six boys...

...all more profoundly afflicted than your son.

For God's sake! How afflicted
does he need to be?
It's a school, Lorenzo,
like any other school.
- And it's full of doctors?
- Yes. Some of the cleverest in America.
- What colour is that cross?
- Red.
That's right. It's red.
I'll speak to your parents for a second.
Leah's gonna take your blood pressure.
I'll be right back.
I'll just put this around your arm.
You've had this done before, haven't you?
Look, it's important you both
know exactly what's going on.
Cyclophosphides are no picnic.
This is chemotherapy.
We're gonna be suppressing
his immune system. It's very high-risk.
We'll need to keep him here
at least three weeks.
Now, Lorenzo is still walking,
talking and communicating.
But that could all change.
Now, knowing all this, do you
still want us to go ahead with it?
Given the alternatives, yes.
The faculty is very grateful
to Lorenzo for doing this.
Ladies and gentlemen, this is Lorenzo
Odone, whom I've spoken to you about.
Now, young Mr Odone,
you need to come with me.
You are getting so big!
Now, I'm gonna put you up here
so we can all see you, OK?
Attaboy.
Ten weeks after diagnosis
we observe hemianopia...
...with transient horizontal nystagmus.
The pupillary light reflexes
are still intact...
...and, as yet, there's no optic atrophy.

However, there is evidence of
early occipital-lobe involvement.
Why are all these people here?
- I beg your pardon, Lorenzo?
- Why are all these people here?
He asks why all these people are here.
Well, they're all doctors...
...and they want to learn
how to help other boys in the future.
Other boys with the boo-boo?
- Yes, darling.
- Mm-hm.
Thank you, Lorenzo.
Now, in the scanning speech,
we look for both ends of the pathology:
...centrally for the dysphasia,
and peripherally for the dysarthria.
Now, Lorenzo, would you
walk for me, please?
Attaboy.
That's right. Hold my hands.
That's right.
Two months ago there was simply motor
lag. Now note the characteristic gait.
It's due mostly to hyperreflexia, but
exacerbated by the encroaching paresis.
You're doing very well. Keep coming.
Only if you stop talking like that.
Hello, Mr Odone. Have I got that right?
- Odo-ne.
- Odo-ne? I'm sorry.
Ellard Muscatine.
I'm with the ALD Foundation.
We heard about your boy Lorenzo,
and we'd like to offer you some help.
You're a doctor?
Doctor? Heck, no. I'm a machinist from
Allequippa, PA, but I'm an ALD parent.
This is my second time around, so I know
exactly what you're going through.
My wife Loretta and I,
we run the foundation.
We organise counselling,
conduct seminars, fund research.

We have 500 member families,
not only American...
...but from Portugal,
Israel, Japan, Australia...
And we're growing all the time.
We wanted you and Mrs Odone
to know that you're not alone.
Hi. Ellard Muscatine.
Welcome to the conference.
- Augusto Odone.
- Michaela.
Oh, very nice to meet you.
Please come in.
This is my wife Loretta,
and these are the Odone.
Great. I'm so happy
you were able to come.
Because I think a lot of it is denial.
We don't want to say anything's going
on. We're strong and we can handle it.
But this is the place and
this is the time to let it all out...
...let the barriers come down...
...and to share your feelings
and get it off your chest.
It's hard to believe that
things can get worse.
But they will.
One thing nobody wants to
talk about is what happens...
...or does not happen, between
the two of you in the bedroom.
A whole year
we couldn't touch each other.
My husband stood by me all the way
but, oh my, does it test the men!
- And the weak ones just up and go.
- Even the strong ones leave.
My guy hung in there when our first boy
took sick. Then we had little Jake tested.
Arlen wanted a whole bunch of boys,
a whole ball team.
He's gonna have 'em too...
with some other gal.

We'd like to thank the parents...
...who gave so generously to the fund
for the immunosuppression trial.
The doctors have said that
this experiment contributed greatly...
...to the understanding of ALD.
Betty and Tom Knowles,
\$250 in memory of Corey.
Dr and Mrs Liebowitz,
\$500 in memory of Joel.
Mr and Mrs Higgins,
\$1,000 in memory of Adrian and Julian.
26 people have sent in
recipes for the newsletter.
Now, we still need ideas for
snack foods and breakfast treats.
Remember, all recipes should be
low-fat...
...and use only the foods
allowed on the institute diet.
- Excuse me.
- Yes, ma'am?
Our son has complied with this diet...
...but his levels of saturated C24 and
C26 have risen for two months in a row.
That's exactly what's happened to Jaybird.
Ah, well, perhaps before we talk
about publishing cookbooks...
...we should ask ourselves
if the diet is working at all.
- Shouldn't we?
- Damn right we should.
This is not the way we do things here.
But there are two families here
with this paradox. Maybe there are more.
Shouldn't we open it for discussion?
- My boy's levels are rising.
- Now there are three families.
So maybe we should...
Could we have a show of hands?
Then we'll see how many
families there are.
You don't understand. This is a formal
pilot study. It has to run for six months.

We're not scientists.
We don't interpret experiments.
That's the solemn
responsibility of the doctors.
Come on, Ellard!
Let's have a show of hands.
No, that would be misleading.
The medical folks call
this kind of evidence anecdotal.
- What's wrong with a show of hands?
- It wouldn't have any meaning.
- Excuse me. May I say something?
- Sure.
The only way that the doctors can get
useful results is with a strict protocol...
...and statistical samples
in a control group.
And a proper time frame.
Doctors have to be careful.
Clinical trials must withstand
a tremendous amount of scrutiny.
This is the way that
medical science works.
That's the only way the scientists
can get the information they need.
So what you're saying is that our children
are in the service of medical science.
How foolish of me. I always assumed...
...that medical science
was in the service of the sufferers.
Yes. Uh, thank you.
Uh, now I think it's time
we get back to our agenda.
Why? So we can discuss further salvaging
our marriages and managing our grief?
What about the children?
No one here is discussing the children.
Thank you.
Now if Mary has nothing further to add,
I would like to introduce Dr Chapel...
...to talk about the nasogastric tube
and suction machine.
Would you all join me
in giving him a very warm welcome?

Thank you, Madam President.

Thank you, Ellard. Ladies and gentlemen...

- Now hold my hand.

- Yes, sweetie.

- Now the story.

- What story is that, sweetheart?

La notte di San Lorenzo.

San Lorenzo, who is...?

My patron saint.

And saint of my father's village.

That's right. And what happened to him?

He was in Rome.

Mm-hm.

And... I forgot.

Well, many years ago...

...the bad guy says to him

"Bring us the riches of your church."

And Lorenzo, he brings them

the beggars and the sick people...

- ...and he says...

- "These are our riches."

Yes!

- Bravo, Lorenzo, bravo.

- That's wonderful, sweetheart. So clever.

And tonight, August 10th, is...

La notte di San Lorenzo.

The night of the shooting stars.

When anything can happen.

Micha...

Sh, sh, sh.

When we first went to the Comoros,
what did we do?

- We got to know the country, right?

- Yes.

We studied. We got to know
the language, resources, its laws.

We studied, right?

We should treat Lorenzo's illness
like another country.

- I don't quite see the analogy.

- All right, all right.

- ALD has many dimensions, right?

- Yes.

So in order to understand it, we need

a command of genetics, biochemistry...
...microbiology, neurology, ology-ology...
Augusto, we don't have time
to go to medical school.
Michaela, the doctors are in the dark.
They're groping in the dark.
They've got Lorenzo
on a turvy-topsy diet.
And that bloody immunosuppression
is brutal and useless.
Michaela, we should not have
consigned him blindly into their hands.
He should not suffer by our ignorance.
We take responsibility.
So... we read a little.
And we go out and inform ourselves.
But... to miss time with him
while he can still speak to us...
Yes, I know, I know.
But he expects it of us.
I want to take Lorenzo off the diet.
He's been eating cardboard for 19 weeks,
and what's it getting us?
- And feed him what?
- Normal foods. Things a child likes.
Full of the long-chain fats
that we know destroy his myelin?
Look. On the diet,
his blood fats are still rising.
- Yes, I know, Michaela.
- It doesn't make any sense.
But we don't know enough.
We don't know enough.
We don't know it clearly enough.
Here, Michaela,
let me show you something.
All right, here.
Un piccolo acquario.
- A kitchen sink?
- Yes, yes. Little kitchen sink.
All right. Now here is the tap. Mm-hm?
And here's the sink basin
and the plughole, right?
All right. Very long-chain saturated fats

are introduced by what we eat, right?

- Yes?

- Now, also produced by the body...

...or manufactured by the body,
these very same fats.

- Biosynthesis.

- Biosynthesis, right.

Now, normally they are not harmful...

...because this enzyme
eliminate the excess, right?

But in Lorenzo, this enzyme
is defective from genetics.

His plughole is blocked, right?

Yes.

We know that very long-chain saturated
fats are made up of carbon atoms.

C2, 4, 6, 8...

all the way up the chain, right?

But in Lorenzo,

the saturated C24 and C26...

...rise to four times the normal level.

OK, now, here's where we have

a little paradox, a mystery, OK?

Why, when we reduce the dietary intake
of saturated fats...

...does the level in our sink, which
we would expect to go down, go up?

So, logically, we should
take him off the diet.

Well, Michaela...

...just as logically, we should not.

Because let's not do
what the doctors did.

Let's not act without knowing why.

Why, when we turn off this tap,
does the level in our sink rise?

I married a plumber.

You married a man with a simple mind,
who asks simple questions, that's all.

Here, Michaela. Brain food.

- Come on.

- Oh. Thank you.

Polish rats! I think I have
an explanation for the paradox.

Lorenzo, kiss your clever mother.
Polish rats with a fatty-acid storage
disease. Let me use your kitchen sink.
Here's our tap for what we eat.
And here's our tap for biosynthesis.
I see. Biosynthesis. Mm-hm.
When the rats were deprived
of a specific fat in their diet...
...their body cells compensated
by overproducing it.
- So if this holds true for humans...
- Then the diet is useless...
...unless we can stop it overproducing,
slow down biosynthesis, s?
Yes, and there's more. And for this,
I deserve two kisses, my darling.
In the summary, it talks about
the concept of fatty-acid manipulation.
- What's that?
- Well...
...they stop the rats
producing one kind of fat...
...by loading their diet with another kind.
So maybe we could stop Lorenzo's body
from producing C24 and C26...
...by loading his diet with another kind
of fat, one that's less harmful.
We should have this translated
as soon as possible.
I have some news too.
It's a letter from Omouri.
He wouldn't open it until you got home.
- Omouri.
- Yes.
Michaela, by tomorrow morning...
...your Polish rats will be
speaking to us in English. Hm?
I've been thinking.
I found that article by accident.
I just as easily could have missed it.
It was written by a Polish biochemist,
who I'm sure knew nothing about ALD.
Well, Michaela, still it gives us
a new line of inquiry.

Yes, but it could take months.
And there will be other leads that take more time, and it's time we don't have.
All these experts, working in isolation, each one on his own piece of the jigsaw.
Of course, a symposium is the best way to accelerate the exchange of information.
In that sense,
it's a very good idea, Mr Odone.
Only... May I say something?
Have you any idea how many children in the United States die every year...
...from choking on French fries?
Many more than from adrenoleukodystrophy.
Ours is what is known as an orphan disease.
It's too small to be noticed, too small to be funded...
...especially with the iron hand of Reaganomics.
So while, as I say, this remains a very good idea, it's a luxury we can't afford.
Well, we appreciate that, so we have prepared a budget...
...based on 40 participants for two days.
We think it can be done for \$35,000.
My wife and I will raise the money.
- We can't ask you to bear the cost.
- Oh, no, no, no, no.
That's the least of our concern.
And of course, your institute will not be at risk...
...because the Odones will underwrite any shortfall.
And we took the liberty of drafting an invitation list.
Forgive me, Dr Nikolais.
We wish to make two conditions.
We would like the symposium to emphasise therapy...
...and Michaela and myself would like to participate in the discussion.
Martha, I'm afraid we'll have to

add to your workload...
...but it's in a very good cause.
We've decided to convene
the first symposium on ALD.
We should notify the Muscatines.
Of course. The foundation could
help with the arrangement.
They could even, perhaps...
find some funds.
How about we hook it to the back of
the next Foundation Family Conference?
- When would that be?
- Next summer. 4th of July.
- That's nine months away!
- It will take us all that time...
...to invite those busy doctors
and raise the money.
- I don't think so.
- What's your time frame, Mrs Odone?
- Five weeks from now. November 10th.
- That's not possible.
Oh, I think it is.
Pardon me,
but what is the point of rushing?
As ALD parents, we both know
the answer to that inane question.
If you want this to happen,
you're going about it the wrong way.
At least we are going about it.
- Sorry, I don't understand.
- He wants his diaper changed.
Mrs Muscatine, look... Hello?
Hello?
They should be hung by their eyelashes.
- They won't help?
- It doesn't look that way.
- Good boy. I'll take him.
- No, I got it.
- What'll you do? Mortgage the house?
- Not until I have to.
Michaela!
I've spent two months pulling
on the heartstrings of Washington...
...to raise money for multiple sclerosis,

sudden infant death and cystic fibrosis.
Then why exclude adrenoleukodystrophy?
Because I also cover politics,
the arts, women's issues and stuff...
...and my readership likes
to have a little balance.
I cannot do another medical story
right now. Maybe in another month.
Joyce, I think you should meet my son.
My friends...
This is so generous.
You know, Augusto, our wives
are eager to form a committee...
- ...to, perhaps, help with hospitality.
- Oh, wonderful, wonderful.
Not only will we be saving money,
but they'll be extremely well fed.
For breakfast, French pastry, correct?
Lunch, UN finger food.
The British will do afternoon tea.
And for dinner, I know
a marvellous Italian cook.
Are you needin' another pair of hands? I'll
lick envelopes, serve coffee, whatever.
And this is for your boy. I grow
the best organic produce in Virginia.
- Thank you.
- You don't remember me!
Wendy Gimble. Foundation Family
Conference. I yelled louder than you.
- Yes, of course. You have two boys.
- We lost Jaybird, but Jake here is fine.
We think what you're doing is fantastic.
Hello, Jake. Come on in. Thank you.
When I read about what you were doing,
I thought "It's time we did something."
- Please, come in and meet the others.
- Is that Lorenzo?
Yes. Lorenzo, this is Jake.
He's a young man of your age.
Look, Lorenzo, a great big pumpkin.
Let's go down and feel how big it is.
What, sweetheart?
I'm sorry, Lorenzo.

Let's try that again.
This morning I could still understand him.
When we can clone the ALD gene,
we can identify the deficient enzyme...
...mass-produce the gene,
implant it into ALD sufferers...
- ...and normalise their metabolism.
- How long would that take?
Seven to ten years.
You see, science has its own time...
...and, very often, any new advance
can be a matter of serendipity.
For the last six months, all
our ALD boys have been on a regimen...
...which excludes saturated C24 and 26.
But despite this restriction
in the diet...
...these long-chain fatty acids
have remained the same...
...in some cases even increasing.
Now, this compensating increase
I put down to biosynthesis.
But, Gus, if you could maintain the diet...
...and somehow inhibit biosynthesis,
you'd have a therapy.
No, you wouldn't quite have a therapy.
You would have a way of
lowering the fatty acids to normal.
If you wish to inhibit biosynthesis...
...have you considered
fatty-acid manipulation?
There is some literature,
a rat study, Russian or Polish.
Polish. Straszak.
I have copies right here.
Polish Journal of Biological Sciences
1979, Volume II.
They loaded the diet with one fat
and decreased biosynthesis of another.
Yes, I remember this article.
And also in Canada, they have seen
the same thing in miniature swine.
As a matter of fact,
I've seen it in human cells.

In human ALD cells.
From patients with ALD,
I took fibroblasts - skin cells, OK?
Each one carries the same genetic defect.
I incubated them with oleic acid and
reduced the saturated C24 and C26...
- ...by more than 50 per cent.
- Excuse me, Doctor.
You said oleic acid?
Yes, monounsaturated C18,
the main component of olive oil.
- Surely this is the basis for a therapy.
- Slow down.
These are studies in cultured cells. We
don't know it'll work in a human being.
Well, then, take the olive oil
and try it in a patient and see...
Augusto, olive oil is forbidden

in the diet:

Yes, but then use whatever
Dr Rizzo fed his fibroblast.
Pure oleic acid would be very toxic to
an intact organism, an animal or human.
It would need to be the triglyceride form,
which is edible, but that's not available.
All right, can't you take ordinary
olive oil and extract the C24 and C26?
You could, but it's a very complicated
procedure and would be very expensive...
...especially to produce the quantities
for a clinical trial.
Have you contacted chemical companies?
No one will tool up for that.
Not for an experiment,
not for something with no market.
- Then you haven't tried?
- No.
If we were able to get triglyceride,
then we can change all that, right?
Yes. It has to be triglyceride
to be edible.
Edible form. Triglyceride.
No one here can help you.

Then do you know anyone else who does?

I'll send you back to the switchboard.

- Which extension, please?

- Research and development.

R&D.

- I need a triglyceride form of oleic acid.

- Your name, Doctor?

- No, I'm not a doctor.

- Are you with a company?

No, I am not with any company.

I'm the mother of a sick child.

- A mother?

- That's right.

- And you want...?

- Oleic acid.

- The lines are busy.

- I'll wait.

Papa makes you

spaghetti al pomodoro...

...seasoned with basilico,

the royal herb for our prince.

Badabib, badabab, badaboom.

Come on, Lorenzo, take a little bit.

That's a boy.

The best lead

came from the symposium:

...oleic acid in the triglyceride form.

Now it's our only hope for Lorenzo.

Don't fret, Mrs Odone.

You will hear from him within the hour.

- You can be sure of it.

- Thank you. That's 301...

Don't worry, I have the number.

- Thank you very much.

- You're welcome. Bye-bye.

So, as the swallowing reflexes weaken,

he's less able to handle his own saliva.

We'll all have to be pretty vigilant. We

really have to stay on top of this thing.

If we allow any saliva to get down into

his respiratory tract, we block his airway.

We don't wanna do that.

Here we go. Put your

thumb over the valve.

When you don't want suction,
release your thumb.
Hi. It's ProtoChem again.
I'll connect you to our Mr Pellerman.
- I believe you want some oleic acid.
- Yes, in triglyceride form.
You're lucky. We're testing a glycerol
trioleate here as an industrial lubricant.
Industrial? Then... is it fit
for human consumption?
I don't see why not.
It's a purified olive oil.
Without saturates? Pure monounsaturated
C18 in triglyceride form?
- Yes, ma'am.
- You're sure?
It happens we have one bottle here,
sitting idle on the shelf.
Marvellous! How can we
get our hands on it?
- Sorry. Go ahead.
- How can we get our hands on it?
This is... beautiful.
- And it's entirely harmless?
- Gus, you're talking to an Italian.
- It's only olive oil.
- Yes, that's harmless. It's like... sugar.
And yet, to a diabetic,
sugar can be lethal.
You see, the trouble is we don't know to
what extent Lorenzo can metabolise fats.
Yes, well, Gus, it's been seven months
since Lorenzo was diagnosed.
Now he is silent. He's immobile.
Augusto, I am a scientist...
...and I'm of absolutely
no use to you whatever...
...unless I can maintain my objectivity.
And I am not a scientist. I am a father.
And nobody can tell me what dressing
I put on my kid's salad, OK?
Augusto...
This science of medicine.
You know, it's not like physics.

There's no mathematical certainty.
And because we deal with human beings
who suffer, it can appear heartless.
I know.
You realise that any collaboration
of mine would have to be unofficial?
S, s, of course. Now, the dose.
We think 40 grams a day.
- That's too much. Say 30.
- 30?
Yes. Any more than that
might damage your son's liver.
Darling, they're about to start.
We're going to send this blood away
to establish a baseline, my brave boy.
Because today we all start
the fight against the boo-boo.
There. All done.
Lorenzino, this year we celebrate
Thanksgiving a little early...
...with a fine barracuda
like we used to eat in the Comoros, huh?
And Papa has cooked it
with the aromatic dill.
And now...
...we add the special olive oil
which Mama found.
Hm? All right?
There we go.
Deirdre.
All right, Lorenzo. Here we go.
- There we go.
- You did good, buddy boy. Real good.
Your Aunt Deirdre means "well", darling.
In this house, we cherish our adverbs.
I expect you to do the same
when you get your voice back.
- Hello?
- Mrs Odone, this is Dr Nikolais's office.
I have Lorenzo's results. There's been a
small drop in the saturated C24 and 26.
- About 15 per cent.
- 15 per cent?
Dr Nikolais said not to get carried away.

It could be a spontaneous variation.
- Am I allowed a tiny squeak of joy?
- We'll know more next month.
Thank you.
Michaela!
Augusto! Get something
to hold down his tongue!
Oh, my baby!
So, this is a kind of seizure,
like epilepsy?
No, not a seizure. It's a paroxysm.
It's triggered by saliva in the windpipe.
- But we suction him.
- Regularly.
I know, but even so, some saliva
gets caught in the trachea.
In any other child,
a cough would get rid of it.
In Lorenzo, it becomes
a scrambled chain of reflexes...
...that amplifies into
what you have just seen.
If this happens again,
what can we do about it?
Just help him try to ride it out.
We're all flying blind here, folks.
The best I can offer is sedation.
But if it's not epilepsy, then he's aware
of what's happening while it's going on?
Well, it's possible.
And if he has another episode,
we could talk him through it.
It's possible, Michaela.
It's possible.
- S, s. A 50 per cent drop, right?
- That's correct.
Thank you very much. Thank you!
Fantastico! Fantastico!
I very well understand that we are not
scientists, but we have observed this...
Let us do it our way,
Augusto. Trust us.
- I've got to go.
- OK. Thank you.

Goodbye.

- Nikolais says it's very interesting.

- Interesting? A 50 per cent drop?

But it's too early to draw a conclusion.

Rizzo might consider a trial.

And he asked us

not to tell the other parents.

- What?!

- It's immoral. Something finally...

- The parents have to know.

- We'll tell them. They can judge.

- The foundation has a mailing list.

- We'll call the Muscatines.

I can eat crow

in the name of a good cause.

Michaela...

Mm! Delicious! That was worth
driving 300 miles for.

- Now, my friends... dessert.

- Here, let me move this.

And Loretta... a little science, hm?

Thank you.

"Dear ALD parents..."

- You want us to send this out?

- Yes. We'll pay for copying and postage.

But you're advocating a therapy.

No, we're merely reporting

a positive advancement in the diet.

It would be wrong to keep it

from the other parents.

Mrs Odone, we have an advisory board
of eminent doctors...

...and we take our guidance from them.

They are the ones

with the medical degrees.

Yes, my dear, but Nikolais

already knows about this...

- ...and the wretched man does nothing.

- Because he is a responsible scientist.

- No, because he has another agenda.

- All right, Michaela. Calmati, calmati.

You know, Loretta, sometimes...

...the interest of the scientists is not
the same as the interest of the parents.

Scientists are human
and sometimes they can be wrong.
As president of the foundation,
you represent us, the families.
And you serve the families best
by informing them.
And all we ask is that you please
send this letter to them, that's all.
Our parents suffer enough without
being made the victims of false hopes.
We can't give credence to every jerk
with a pocketful of apricot seeds.
Excuse me, this is not Laetrile. We're
talking about an extract of olive oil...
...an idea that was put forth
by the scientists at the symposium.
And it works in Lorenzo.
It works in an ALD boy
to a degree that is significant.
- Very significant.
- Other parents have a right to know.
We know that this is a deadly disease,
so they have a right to choice.
And if they feel as we do,
they can put pressure on the doctors.
Because, as parents, we should
challenge these guys. We push them.
Unless someone is willing to question,
to provoke, how would there be progress?
Well, we feel there is progress.
Loretta, we know that, but all we say is
start a dialectic with the doctors.
Are you telling us what to do?
We're asking you
to disseminate information.
You gonna teach the doctors?
Where we come from, that's arrogance.
- Arrogance!
- Yes.
It is... arrogance.
It comes from the Latin word... arrogare.
You know it? You know
the root? What it means?
It means to claim for oneself.

That's the root.
It means to claim for oneself.
And I claim the right
to fight for my kid's life.
And no doctor, no researcher, no bloody
foundation, has the right to stop me...
...from asking questions
which might help me save him!
And you have no right to stop
the sharing of information!
- So you think about it!
- Our job is to be there for the parents.
To comfort them,
not to get them stirred up.
If the doctors think you have something,
they will tell us in their own good time.
- Their own good time is not our time.
- What? They are so powerful...
They are so powerful
that you would be silent?
They are not gods!
Do you know, this acquiescence
is so disgusting!
You think you know so much.
Let me tell you something!
When Michael got sick, we looked for
anything that might help him.
And the best thing that happened?
He was taken quickly.
Now, Tommy... he has lasted three years.
For two of 'em, he's been
without his sight, his mind...
...everything that makes him
a human being. He's a vegetable!
Oh, boy! If you would stop all this denial,
you wouldn't do a thing...
...to prolong your boy's suffering
and indignity one minute longer.
Has it occurred to you that maybe
he doesn't want to be around any more?
S, s. Thank you.
It has to be a mistake.
No, Nikolais says not.
- Augusto...

- Oh, sorry.
- Should we risk raising the dose?
- No, he's too fragile.
Any more might harm his liver.
Lorenzo, listen to Mommy.
You're going to have to be brave
as only you know how.
We're gonna count together,
you and I, all right?
Listen to Mommy's voice
and the boo-boo will let go of you.
One, two...
...three, four...
Michaela...
You know, I've been a nurse for 18 years,
eight of them spent in ICU paediatrics.
And I know that you can't always
play by the rules, but...
...this boy shouldn't be at home.
He should be placed
in a properly equipped hospital.
Why don't you say what you mean?
I'm not comfortable with this situation.
Well, Lorenzo and I aren't comfortable
with your lack of comfort.
I can't continue to be a party to this.
I gotta give you my notice.
I'll stay until...
- No, you should finish tonight.
- Michaela! Go easy.
Your agency will receive
a cheque in the morning.
Look, Ruth. We're all
a little strung-out here.
She's talking about placement, Deirdre.
It's a euphemism for "hospice".
Lorenzo has enough to endure. We will
not expose ourself to doubt and despair.
She's exhausted. That's all it is.
Look, I don't know.
Somebody had to say something.
Good luck.
Buonasera, Odone.
Look what I found.

Look at this. Would you look at this!
Let me show you.
Where are we? Right here.
That was June of '83, just 21 months ago.
You know, it's time you guys
take it easy on yourselves.
Deirdre...
If we knew why it only work halfway...
...then we might know what to do next.
Augusto, how many mornings
have I found you asleep...
...under a pile of research papers
with the lights still on?
And then you wake up
and drag yourself into the office.
How long can you keep this up?
If you get sick - and you will -
what are you gonna do for money?
What are you telling me?
For God's sake, he is my kid.
Yeah, so are Cristina and Francesco, and
it's been a year since you've seen them.
Listen to me, OK?
There has to be a life beyond Lorenzo.
What are you telling me?
That I should give up on this now?
Oh, man. We both know that even if
you get his levels down to normal...
...his brain can't fix itself.
How much myelin does he have left?
Do you ever ask yourself that?
- Deirdre, now that's enough.
- No. Don't bullshit me.
I know you do... but she doesn't.
Not ever.
You have to help me with her.
She doesn't eat, she doesn't sleep.
I'm afraid for her.
I think she's losing it.
You've seen how she is with him.
She just can't let him go.
Poor Deirdre.
Spoken as only a woman who's
never had a child could speak.

Michaela, Deirdre was
speaking out of love.
I am only telling you what I see.
For both your sakes,
there has to be life beyond Lorenzo.
Do you think that he has no voice?
No will to live? He asserts it through us!
If you can't see that,
there's no place for you here!
Michaela, for God's sake,
she is your sister!
- And I think you're losing it, Michaela.
- Well, then, I think you should go.
Augusto, help her pack her bags.
I'm going back to our son.
You think I'm crazy
because I speak for our son?!
I am so sorry.
I never wanted this to happen.
How can I? How can I enjoy
anything when he enjoys nothing?
How can you talk to me about loving him
when you trivialise him into...
No! No!
- Mrs Odone!
- Get a tube.
Do you have the tube?
Don't nod, Nancy Jo. Say "yes".
My attention's on Lorenzo.
Darling, look at me. Listen to
Mommy's voice. We're gonna count.
One, two, three, four...
I'm sedating him as much as I dare.
I don't know what else to do.
How can he endure this
for so many hours?
Augusto...
I don't think he'll have to
endure it much longer.
Michaela, let me take him.
- You need rest.
- I'm fine.
I could use a cup of coffee, though.
Lorenzo... Lorenzo, listen to Mama.

Can you hear me, my darling?
If this is too much for you,
my sweetheart...
...well then you fly, you fly
as fast as you can to baby Jesus.
It's OK.
Mama and Papa will be OK.
I have rarely seen anything
like this boy's tenacity.
They have a bed available upstairs.
No, no, no. In a hospice, no.
It'd be easier. On everybody.
But I would not do honour to Lorenzo.
Michaela. Come.
- What?
- Come. Come on.
- Nurse.
- Yes.
Now, today we eat, moglie mia,
every last mouthful.
- I'm not hungry.
- No, no, no. You eat.
Sit.
Michaela, you sit. Sit.
From tomorrow morning,
the Odone's need all their energies.
Now listen. We set out to
normalise Lorenzo's blood, right?
And with the oleic oil, we got it
half-right, but that was luck.
- It was rather more than luck.
- No, it was luck. Merely observation.
Rizzo observed something
in a test tube, right?
We tried it on Lorenzo.
Rizzo observed
a 50 per cent drop in fibroblasts.
We observed
a 50 per cent drop in Lorenzo.
Michaela, that is luck.
That is observation.
That is all it is.
It is not understanding.
And until we understand

why this work only halfway...
...how can we expect
to succeed all the way?
I need to understand, Michaela.
You need to understand.
So, tomorrow we go back to the library.
No, no, no. We review all the literature,
everything on fatty-acid metabolism...
...every word published in the last decade.
So, eat. You eat.
Whatever energy or time I have left
I want to spend with Lorenzo.
You will not have to leave him.
I will go to the library.
I make copies for you,
I bring it home for you.
Augusto, we are on our second mortgage.
You can't afford not to go to work.
Michaela, I will work.
I'll fit it in somehow.
Michaela, this is important. I need you.
I need you, Michaela.
So eat.
Brava! Bravissima! Bravissima!
Betty! Betty!
All these fatty-acid studies concentrate
on the middle of the chain...
...because the medium-chain saturates
are implicated in cholesterol.
So what do these researchers do?
Think cholesterol, cholesterol.
C12. C14, C-bloody-16!
- Augusto, what are you looking for?
- I am looking...
- ...for the long end of fatty-acid chains!
- All right. Write it down for me.
These researchers should be
doing something about this.
- Write it down.
- Long-chain fatty acids.
C18 through C26.
Saturated.
Monounsaturated, OK?
OK. Now I want you to go off to lunch.

Have yourself a good lunch
and I'm gonna see what I can do.
This is the best I could do
at short notice.
One article from a veterinary
science journal about pigs.
- But it's on your long-chain fats.
- Well, thank you, Betty.
Listen, I am very sorry about...
Oh, well, you're Italian.
...72, 73, 74...
That's it. 75, 76...
...77, 78...
Nice going, Mrs Odone.
That's it, my love. You know
only the strongest, bravest boy...
...only a very special person
like you is chosen to fight the boo-boo.
I'll give him a little water, OK? 20cc's?
Yes.
And, Nancy Jo, why don't you tell Lorenzo
what an excellent job he did?
An excellent job you did, Lorenzo.
Sometimes I wonder, my love, if people
realise how incredible you truly are.
Oh, thank you. Thank you very much.
Is this a new hobby or a nervous tic?
No, this is a simple mind at work,
that's all.
See, each paperclip, Deirdre,
is two carbon atom, right?
- Oh, God!
- No, no, no.
Really is two carbon atom, all right?
So we have C2, C4, C6, you know?
Now, here's what I try to do.
I try to make a chain...
...a very long chain
of monounsaturated fats.
- This is the good guys, right?
- OK, what are these? The bad guys?
Yes. These here...
...is the bad guys, all right?
Now, Deirdre, what I'm trying to do...

I try to understand the relationship...
 ...between the good guys
 and the bad guys.
 So, OK, I am the enzyme, right?
 And I reach out and grab a carbon atom
 and I put it on my chain, right?
 Here is my chain.
 Now, here, you be
 the bad-guy enzyme, OK?
 No, no. Do this for me.
 You be bad-guy enzyme, all right?
 Take this, all right?
 Now you reach out and grab a carbon
 atom and put it on your bad-guy chain.
 I had enough trouble
 with the kitchen sink.
 No, no. You just do this and
 then I explain, OK? All right.
 So let's each start now
 making our chains.
 OK? All right? Do another one.
 That's good, Deirdre.
 Good. We put another one on...
 - Here's the stuff on enzyme complexes.
 - Ah, thank you. Mille grazie.
 - Prego.
 - Prego! Very good.
 - Now, did you make the extra copies?
 - Oh, you bet.
 - Thank you very much.
 - For Michaela? How is she?
 She's fine.
 So here we are. We're making our chains
 more or less the same rate, right?
 That's as one would expect, right?
 But, now, Deirdre, if we were enzymes...
 ...in the bodies of little rats
 and little pigs and Lorenzo...
 ...then the faster I go,
 the more you slow down.
 Now, why would that be?
 Why, the faster I go, would you slow
 down, if we are both separate enzymes?
 It means that there has to be

some kind of relationship going on.
We affect each other some way.
There's some kind of interplay.
But what is it?
What is it?
One, two...
...three, four...
...five, six...
...seven candles.
And Mommy will blow them out for you.
Make a wish.
Michaela! They are the same enzyme!
There is one enzyme for both chains.
It's the same bloody enzyme!
So if we keep the enzyme busy
making monounsaturates...
It distracts it from
elongating the saturates.
Right! So we have a way to trick nature.
Yes, it's a principle called
"competitive inhibition".
So, Gus, do you think
it's a reasonable hypothesis?
I think it's more. You've clarified
the biochemical pathway.
Augusto, I really want
to congratulate you.
This would explain why oleic acid
is only partly successful.
Yes, it's C18, you see.
It's too low down in the chain.
So we add a second barrier. We block
the bad guys further up the chain...
...the saturates further up the chain,
between C22 and C24.
There we stop
the bloody things completely.
- And how would you do that?
- By adding monounsaturated C22.
- That's erucic acid.
- Yes, exactly.
Erm...
- Martha?
- Yes, Doctor?

Among our animal studies,
you will find a file on erucic acid.
With an e... r-u-c-i-c.

- OK.
- Thank you.

You don't believe it will work?
I think what you have done is postulate a
theory that could be of enormous benefit.
But, as for erucic acid,
it creates cardiac problems in rats.
If it's not safe for rats, I don't know
what justification there can be...
...for using it as a therapy on humans.
But Gus, Gus...
...erucic acid is the chief component
in rapeseed oil, right?
Rapeseed oil is a common food
in China and India.
And their rate of heart disease
is far lower than here.
All right, look at these documents.
Cardiac lipidosiis...
...myocardial lesions, cholesterol
deposits in the adrenal gland...
...and damage to the reproductive system.
I'm afraid the weight of evidence
is much too great.
And no human-studies
review committee...
...will ever do anything but discard
erucic acid out of hand.
But the human studies
have been accomplished by history.
They have been eating the stuff
in these countries for thousands of years.
You can't expect me to start a protocol
based on that kind of assertion.
You should examine your protocol...
...when children are dying and
find a way to research these...

- It's common sense.
- We simply have a contradiction.

We seek more information. We do not
dismiss erucic acid out of hand.

Michaela, if I ignore all this evidence...
...and we embark on a therapy
based on erucic acid...
Something goes wrong. What then?
Well, then I suppose the risk-reward
ratio is too unattractive for you.
I beg your pardon?
The life of one boy
is not enough reward for you...
...to risk the reputation of the
institution and the esteem of your peers.
That was uncalled for. Your responsibility
is merely towards your own child.
My responsibility is towards all the boys
that suffer from this disease...
...now and in the future.
Of course I anguish for
the suffering of your boy.
And of course I applaud you for
the efforts you make on his behalf.
But I will have nothing to do
with this oil.
We are not asking, Doctor,
for your anguish or your applause.
We are asking merely for a little courage.
OK. All right.
No, whatever the doctors say,
reason tells us it is a risk worth taking.
But, my friend, we need
a sympathetic collaborator, hm?
If it was in my hands, I would do
anything I could to help, Mr Odone.
I have a boy of my own.
But I don't like our chances.
You know, they said the same thing
about the oleic acid, and here it was...
- ...sitting right on the shelf.
- This is a whole other ball game.
Extracting the saturated C24 and 26
from rapeseed oil...
It's very tricky. It would take
our best chemist at least a year.
And then you would never get it past the
FDA. Erucic acid for human consumption?

I'm sorry, but no one in the country
is gonna touch it.
Well, what about
outside this country, hm?
Uh, I wouldn't know where to send you.
Oh, Mr Pellerman! We're agents
for over a dozen foreign companies.
There must be one that could help.
Maybe all we need to do is look
at the list of the foreign companies.
No, you and your wife
have enough to do.
I'm sure Mr Pellerman would be happy
to make the calls for you.
We'd have to be covered, legally.
If anything goes wrong, this company
is not going to be held liable.
Oh, we would not hold you liable. No, no.
And this... It would be greatly
appreciated if we could circulate this.
"The interplay of monounsaturated
and saturated fatty acids:
...therapeutic application in ALD."
- Wow.
- You wrote this?
Yes. We felt that
if we were asking for help...
...our rationale needs to be very clear.
We've all read your paper.
It's a beautiful piece of biochemistry.
Over a hundred companies
all say "too difficult".
Well, my first impression
was that it's bloody impossible.
But I've been doing difficult
fractionations for 40 years...
- ...and I'd like to have a stab at it.
- How long do you think, Mr Suddaby?
I've only six months
before I retire, so we'll see.
All right. Then I'll let you get on with
it. Call me if you have any questions.
Righto. Bye, then.
Who could this be?

Ah, your good friend Wendy...
...with all sorts of lovely
vegetables and fruits.
- Hi, Michaela.
- Look what you brought us!
Hi, Lorenzo.
Jake's not in school today?
He's not feeling so good.
I'm going for a walk with Mrs Gimble
and we shall be back shortly.
I've given him his oxcarbazepine
and 15ml of water.
- Do you want me to do anything else?
- I'm sure he would love a story.
Do you have a problem with this?
Fine.
- He's had a couple of tantrums.
- Oh, I'm sorry.
It's OK.
- Dr Rizzo got him in the oleic acid trial.
- That's good.
Hi, Jake.
Hi, sweetie.
Thank you for my potatoes.
Say hello, son.
Hi, Mrs...
...Odone.
He saw the way Jaybird went.
He knows what's in store for him.
"They forgot their hunger
and followed the bird."
"They came to an opening in the forest."
"Before them was a little cottage,
gleaming in the rays of the setting sun."
"'Look, Gretel' exclaimed Hansel.
'That cottage is made of gingerbread.'"
"'It really is' replied Gretel,
running up and tasting a bit...
...that she had pulled from the wall."
"'And the roof is shingled
with butterscotch.'"
"'The windowsills are made of chocolate'
declared Hansel, breaking off a bit."
"'The windowpanes are clear candy'

said Gretel. At that moment..."

Nancy Jo, do you think you could muster
just a tad more enthusiasm?

Lorenzo loves words.
He loves the sound of language.

Well, I'm paid to nurse,
not read stories.

You've decided his mind doesn't need
as much nurturing as his body?

What mind?

I beg your pardon!

Nothing.

Get out.

- Look, Mrs Odone...

- Just get out.

I've read up on this disease!

I know what it's done to his brain!

Sh! Lorenzo doesn't need this from
a subliterate with a double-digit IQ!

Face it. The lights are out
and nobody's home!

- Just get out. Go!

- Well, merry Christmas.

- Get out!

- Happy holidays!

And a joyous yuletide!

"Near a great forest
lived a poor woodcutter...
...with his two children,
Hansel and Gretel."

"Times were very hard and
a day came when there was no food...
...except a little stale bread."

"But Hansel..." was like you, my darling.

"He was a clever lad who knew
how to solve difficult problems."

"The woodcutter was very sad..."

Are you going to
keep doing this?

She brought it on herself. She
consigned herself to the outer darkness.

Michaela, Nancy Jo, she was
a good nurse. You train her well.

Yes, but I want someone

to give him more than medication.
Someone who will minister
to his mind and his soul.
- I think I've found him.
- What?
I wrote to Omouri.
I asked him to come and stay with us.
- Omouri?
- Yes.
Lorenzo is surrounded by women all day.
I don't want him to grow up hag-ridden.
But you cannot take a boy
out of his fishing village...
...and bring him here to nurse Lorenzo.
Not to nurse him, to be his friend.
To bring the Comoros into this room.
We cannot uproot this young man
from his family, his way of life.
- Where will he live?
- Here, in Lorenzo's room.
But... he has no English.
He's a Muslim. An African.
We cannot bring an African to this racist
country to be a second-class citizen.
- This is Washington, DC.
- He'll be part of this family.
I'll teach him English.
There's a lot we can do for him.
Oh, Michaela...
Here. Sit down, sit down.
Now, the last time
Omouri saw Lorenzo...
...he was climbing trees.
He was a wild and vibrant boy,
full of life.
In the letter that you wrote to Omouri...
...did you tell him what he will see
when he walks into this room?
I told him he'd see a young man who
was very ill and had need of a friend.
That is all?
How would you have me describe him?
As a biochemical conundrum?
Non vero.

You know he is not that for me.
Augusto, when you look at him,
what do you see?
Tell me the truth.
- How do I tell the man to give up?
- Say his health won't take it.
The hours he's working are daft.
Our expectations were unrealistic.
Look, Don's a man who's been working all
of his life in face creams and cosmetics.
With this oil, he's having the time
of his life. You tell him. I won't.
All right. For his own sake, I'll have to.
Then you can call Mrs Odone and
tell her that you've pulled the plug.
- I'd best leave him be.
- I think you're right.
Omouri!
Lorenzo... Omouri is here.
- Morning.
- Good morning, Mr Suddaby.
There's a bottle of pure erucic acid
triglyceride on my bench.
Will you see that it gets to young
Mr Odone as soon as possible, please?
I'm off home now. Bye-bye.
Goodbye, Mr Suddaby.
Well, we'd better get on with it.
Four parts our old friend, the oleic.
And...
...one part erucic.
And the journey begins,
and like all good journeys...
...with food.
Where's the wretched nurse?
I'm gonna take my baseline myself
if she doesn't get here soon.
A month is much too long.
If we check my blood every week...
...and I have a cardiogram, we should
know enough to start Lorenzo sooner.
Oh, at last!
Hi.
How's the mother tiger?

Augusto didn't tell you?
I'm here to be Lorenzo's rat.
That's a very kind offer,
but I can't let you.
I'm a carrier, just like you. My blood
levels are just as high as yours.
I've had my baseline taken...
and I'm starving.
Oh, I have been wanting
to meet Lorenzo's main man.
I am content
to greet Aunt Deirdre.
Well, it's good to meet you too.
Now, now, Michaela. I want no argument.
Michaela, you cannot test it.
- Lorenzo needs you fit and well.
- So you would put Deirdre at risk...
- ...without even discussing...
- Hey! I backpacked all through India.
I must have eaten
rapeseed oil up the wazoo.
- Ah, I've been fasting all day.
- All right, go ahead. Try it.
OK, here goes.
So... does it taste awful?
- No? Good.
- It's good.
Good. Eat, eat.
Your sister had no side effects?
None at all. If we can normalise the
levels of a carrier so quickly, who knows?
- We'll start Lorenzo immediately.
- Marvellous.
- We're all terribly grateful.
- No, no.
Not to mention Deedee, the family rat.
- What dosage will you give the lad?
- We don't have time to be conservative.
We've decided on eight grams.
I ride an old paint.
And lead on an old Dan.
I'm goin' to Montana.
To throw the Hoolihan.
- Hello.

- Mr Odone?
Odo-ne, yes.
Look, we have a problem
with this blood sample.
You have a problem?
What is the problem?
Could there have been
a mistake in the labelling?
No. No mistake. Why?
Well, we ran the assay twice and
the levels of C24 and C26 read normal.
They read normal?
Well, uh, I...
Do you have the sample in front of you?
Yes.
- What is the name on the sample?
- Lorenzo Michael Murphy Odone.
It's Odo-ne.
No, there's no mistake.
- But thank you very much.
- OK, bye.
Whoopie-ti-yi-yo.
Get along, little dogies...
- What's going on?
- His levels are normal.
- Play! Play!
- Oh, that's wonderful!
Now, drink it up, son.
Every last drop. Good.
Mom says this is
the only bottle in the world.
Now that we have destroyed
Lorenzo's blood fats...
...I'm sure that Mr Suddaby
will make us plenty more, huh?
Mom says this is bootleg.
I know this is only
a fraction of what it cost...
- No, no, no, Wendy.
- You gotta take it.
No, we work on the barter system.
Our oil, your produce, huh?
There aren't that many
potatoes in the world.

OK. Here you go.

So, when will you tell Nikolais?

Well, we told him and the other doctors
and we sent all the figures.

- What did they have to say?
- They deliberate. They want more study.
- Wendy, that's enough.
- So the other kids have to wait?

We know what to do
about that, don't we?

The doctors had a very hard time
swallowing the first oil.

They want to see how it goes
with Lorenzo on the second.

- But we don't have time, do we?
- No.

So we leave science
to its own concerns, huh?

- Merry Christmas.
- Goodbye, Jake.

What happened to the suction machine?

There's no need, Michaela.

Not for four hours.

I turned the machine off.

All last night he made
to swallow for himself.

Augusto! Augusto!

We hope to make
an announcement quite soon...

...about a new development
in our diet therapy.

It's expensive but,
with the help of the government...
...and of this wonderful foundation...

...we are going to start a trial
before the end of the year.

I can hear from that
that you wish us Godspeed.

Excuse me, Doctor!

Are you referring to the oil
the Odone's have invented for Lorenzo?

- We'll take questions later.
- No, it's a good question.

I should have mentioned it perhaps but...

The Odone's have been extremely active...
...and we are in their debt.
Thanks to them,
we are preparing a protocol...
...for review by
the human-studies committee.
If then we can persuade
the government to fund us...
...then we shall know if this oil is of
more than temporary therapeutic value.
But it works! Lorenzo's
blood levels are down to normal.
It's precisely for that reason
that we are conducting this trial.
You don't expect me
to endorse a therapy...
...just on the basis
of one hopeful observation?
There's two! My boy's been
takin' the oil for six months.
Yes, Ellard, and his blood levels
are down to normal. He's fine.
You are playing with people's hopes.
Where do these Odone's get off, thinking
they know more than the doctors?
- Where did you get this oil?
- The Odone's. They get it from England.
They don't have approval from the FDA.
It's bootleg. Give the doctors a chance...
Come on, Ellard!
It's a mixture of two cooking oils.
Two cooking oils? What's the dosage,
please? What are the side effects of this?
- How would we pay for it?
- There must be a formal protocol...
...before we can raise funds. I understand
it will cost over \$1,000 a litre.
And no insurance company or government
will support you without the approval.
And the only way to get it
is through thorough testing.
That's what they told AIDS people
about AZT, but they fought and got it.
Because they were dying.

They didn't have time to wait...
We padded our walls yesterday!
I want that oil!
There, my darling. That's a sweet boy.
What a big, strong boy.
Yes, my darling. Yes.
You see, Michaela...
...it's as though he is trapped
down in some dark cave.
Because he's lost so much myelin,
he can't find his way out.
Now, we know
his simple functions are intact.
He breathes, he swallows,
his heart beats.
And from the outside world,
he receives sensation.
A touch...
...pain, cold.
And here are the primal feelings.
Fear, hunger, desire.
While up here in the neocortex,
the higher brain, locked here...
...are his reasoning,
imagination, memory.
The things that make us each ourselves.
So how does he reach us?
When a simple swallow
is such a huge task?
To find...
To find the way,
the path from his mind...
...to the outside world...
...is like willing himself
through a brick wall.
So he waits, huh?
He waits.
Michaela...
Do you ever think...
...that...
...maybe all this struggle...
...it may have been for
somebody else's kid?
Yes.

But I promised... I promised him...

...his world would never be silent.

He would never be alone.

Yes.

"One morning,

a little rabbit sat on a bank."

"He pricked his ears and listened
to the trit-trot, trit-trot of a pony."

"A gig was coming along the road.

It was driven by Mr McGregor."

"And beside him sat Mrs McGregor
in her best bonnet."

"As soon as they had passed, little
Benjamin Bunny slid down into the road...
...and set off with a hop, skip and a jump
to call upon his relations...

...who lived in the woods
at the back of Mr McGregor's garden."

"That wood was full of rabbit holes,
and in the neatest, sandiest hole of all...

...lived Benjamin's aunt and his cousins,
Flopsy, Mopsy, Cottontail and Peter."

"Old Mrs Rabbit was a widow. She..."

"...earned her living by knitting
rabbit-wool mittens and muffeties."

"I once bought a pair..."

What's the matter, darling?

You don't like the story?

Lorenzo...

You don't like the story?

He does that a lot lately.

- When?

- Mainly at story time.

Sweetheart...

Listen carefully to Mama.

Is your middle name Patrick?

No... Is it Peter?

No, Mommy.

Is it Michael? Michael Murphy?

Yes! Yes!

Only you don't know how to say that.

Will you teach Mommy how to say no?

When you close your eyes,

does that mean no?

Oh, what an idiot!
That was a yes question.
All right. You don't want to hear
any more Benjamin Bunny, do you?
That's an emphatic reply!
Very well, young man.
No more Benjamin Bunny. How could
Mommy have been so thoughtless?
We're going to take all of these
baby books to the children's hospital.
It's time for the big stuff.
Something heroic.
There you go.
You gotta tell us what you want.
The Once and Future King by TH White.
"The boy slept well in the woodland nest,
where he had laid himself down."
"At first, he only dipped
below the surface of sleep...
...and skimmed along
like a salmon in shallow water...
...so close to the surface
that he fancied himself in air."
"He thought himself awake,
when he was already asleep."
"He saw the stars above his face...
...whirling on their silent
and sleepless axis...
...and the leaves of the trees
rustling against them."
"And he heard small changes
in the grass."
"These little noises of footsteps
and soft-fringed wing beats...
...and stealthy bellies
drawn over the grass blades."
"A rattling against the bracken at first
frightened him, but interested him."
OK. Is it your thumb?
Is it your index finger?
Your middle finger?
Your little finger?
It's your little finger. You think
you can move your little finger.

OK. Tell your brain to tell your arm...
...to tell your hand
to move your little finger.
Come on, sweetheart.
Tell your brain to tell your arm...
...to tell your hand
to move your little finger.
Come on, my friend.
What a wonderful thing. A "yes".
And then there'll be
a "could be" and a "perhaps"...
...and maybe even a "shut up, Mommy",
but now we just have to get to "yes".
So tell your brain to tell your arm...
...to tell your hand
to move your little finger.
Come on, my love.
Tell your brain to tell your hand...
...to move your little finger.
- Come on, Lorenzo.
- You can do it, my friend.
You can do it.
Come on, Lorenzo.
And they are born
without myelin, correct?
The only naturally dismyelinated
higher mammals in existence.
And this is passed
from mother to son?
Yes.
Their mother is from Edinburgh.
That's Jasmine.
She doesn't shake, but her male pups do.
- You think you can stop them shaking?
- Well, we hope so.
By implanting nerve cells, we expect
to see the growth of new myelin.
We've been partially remyelinating
rats and mice for ten years...
...and it's repeatable.
But if we could fund this work,
it could be the first in higher animals.
And then in human beings, huh?
Well, in time, yes.

Dr Duncan,
if I help you raise these funds...
...and if we can get the researchers
together to collaborate...
...I think we can achieve
very much in a very short time.
Augusto, we scientists
are a very competitive lot.
Such a collaboration is a lovely idea,
but sadly that is not how science works.
That's not necessarily so, because
remember the Manhattan Project?
28 months. It took them 28 months.
Now, if scientists can come together
to build the atomic bomb...
...surely they come together
to remyelinate some puppy dogs?
Papa called from Italy, darling.
He's missing his Lorenzacchio
very, very much.
But he wants me to tell you
he's making a big dinner tonight...
...a banquet of brain food for
the cleverest doctors in the world...
...who've gathered together to put the
myelin back in the shaking puppy dogs.
And if they can achieve that...
...someday there might be a way to help
all the people who've lost their myelin.
Not only the boys with ALD,
but the people with multiple sclerosis...
...and many other diseases, Lorenzo.
And then think, my brave boy, if they
can ever give you back your myelin...
...you'll be able to tell your brain to tell
your toes, your fingers, your anything...
- ...to do what you want them to do.
- ..what I want them to do.
And then, one day...
...I'll hear my voice...
...and all these words I'm thinking
will get outside my head.
Oh! Now it broke!
This is Charles and this is Harry...

...and they've both been on
Lorenzo's Oil for two years.
My name is Michael Benton
and I'm twelve and a half years old.
I've been taking Lorenzo's Oil
for four and a half years.
I was diagnosed with ALD when I was
13 years old. I'm taking Lorenzo's Oil...
I've been taking Lorenzo's Oil
for three years.
Some of the activities I'm involved in
are baseball, basketball...