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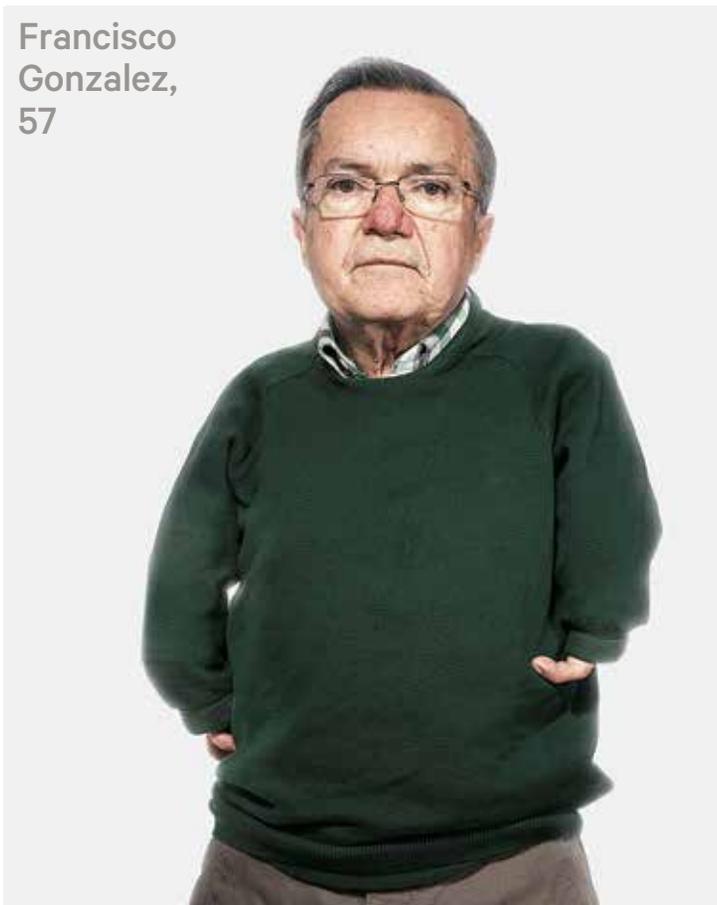


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When the thalidomide scandal erupted in 1961, the drug was soon banned. Yet pregnant women in Spain continued taking it until the 1980s — and the authorities refuse to accept responsibility. *Caroline Scott reports. Portraits by Oliver Haupt*

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THALIDOMIDE IN SPAIN

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Before Lierni Iparragirre could see her newborn third child, Mariano Garmendia, nursing staff whisked him away. “I couldn’t understand why everyone was crying,” she says. “Then they told me: this baby can’t live, he is going to God. They were praying to God he would die, because life would be so terrible for him.”

The staff at the hospital in San Sebastian, northern Spain, wouldn’t let Lierni see her baby that day — June 14, 1977 — but her husband, Jose, saw him. Jose gently explained to Lierni: “We have a boy, but he has no arms, and a very short leg. People are afraid. How can a child with disabilities like this live any kind of life? Everyone is telling us to leave him here and forget about him.” But when Lierni saw Mariano for the first time, a kind of maternal fury kicked in. She said: “No. Give him to me. I will fight for him with everything I have.”

In the little Basque village of Legorreta, Mariano was a freakish sight. Spain was still making the slow transition towards democracy and a free-market economy after 36 years of fascist dictatorship under General Franco, who died in 1975. Medical care was basic, knowledge of Mariano’s specific difficulties almost non-existent. It wasn’t until Mariano was a young man of 20, in 1997, that his mother finally heard the word *thalidomide* — the name of a teratogenic drug developed in postwar Germany to treat morning sickness in pregnant women, and widely promoted throughout the world as a “gentle tonic” for numerous ills.

By then, in Britain and most of the developed world, the devastating side effects of the drug had been known for more than three decades — thalidomide had become a byword for scientific negligence and marketing run amok. The whistle was first blown in 1961 — 16 years before Mariano was born — when doctors began suspecting that the drug was the cause of limb and bowel malformations in newborn babies. By the time it was withdrawn from the market by its producers, Chemie Grünenthal, in November of that year, it is conservatively estimated it had killed 100,000 children through miscarriage, stillbirth and infanticide and maimed at least 20,000 more. Around 3,500 thalidomiders survive worldwide.

In 1973, after a long, landmark Sunday Times campaign against Distillers, the UK distributor of thalidomide — during which the editor, Harry Evans, risked imprisonment by defying contempt of court laws — the British victims finally began to be compensated. The Thalidomide Trust receives £8m a year from Diageo, which acquired Distillers, and, since 2010, £10m a year from the government, which it distributes to the 468 British survivors, now in their fifties, on a points system according to their impairment.

Yet in Spain, where until 2008 the government flatly denied ever importing thalidomide, the scandal is only now fully unfolding. Spanish babies have continued to



General Franco (above) left Spain “like a third-world country” after his death in 1975. “The marketing men could do what they liked,” says one of the Spanish victims

be born with limb deficiencies and facial patterning so similar to those of the 1960s survivors, it is impossible not to look for connections. The youngest suspected Spanish victim I have found was born in 1985.

Now, a trove of official documents, correspondence and doctors’ prescriptions from 1976 and 1977 have come to light that reveal that *thalidomida*, under a variety of brand names, was in fact widely available in Spain throughout the 1970s and perhaps even into the 1980s. Combined with a woeful and ultimately lethal lack of proper controls and safeguarding by the Spanish government, it has resulted in several decades’ more suffering and countless young victims.

Rafael Basterrechea, 49, vice president of the Association of Victims of Thalidomide in Spain (Avite), estimates there may be 250 to 300 victims alive in Spain today. “When these malformations began to appear, no one wrote about it, no one talked about it,” he says. “You have to understand, up until the 1970s people still travelled by mule in Spain. The literacy rate was 60% to 70%; few even had a radio. To a northern European pharmaceutical company, Spain was like a third-world country. The marketing men could do what they liked.”

And they did. Among the damning documents seen by The Sunday Times Magazine, a letter from Grünenthal to its sister company in Madrid, dated December 21, 1961, reads: “You write that you will not disclose the reason for the sales ban to the Spanish doctors and that you will furthermore inform your external staff only partially, not fully.” It points out that doctors in Germany, Belgium, the Netherlands, Portugal, Switzerland and several other countries have received letters warning them of the specific problems with thalidomide. “But if you do not consider such measures necessary [in Spain] then we concur.”

The letter is one of hundreds that has lain undisturbed for half a lifetime in the German state archives in Dusseldorf, and discovered by the UK Thalidomide Trust’s National Advisory Council (NAC). They reveal that, in Spain, Grünenthal showed a breathtakingly cynical disregard for human life on an epic scale.

In October 1962, 11 months after Grünenthal took thalidomide off the market, Jose Riquelme was born in Murcia with a short leg, which was later amputated. He first read about thalidomide in 1980, in a copy of *Interviú* magazine, a winning combination of soft porn and investigative journalism ➤➤➤

“The Franco regime was something you breathed in. You had the priest, the civil guard, the doctor. They were a team, lined up in authority. There wasn’t such a thing as a medical error”

that he found on a rubbish dump near his parents' house in the little town of Alcantarilla. He has that copy, still, with its black-and-white pictures taken by Snowdon of the British thalidomider Terry Wiles. Wiles, also born in 1962, was one of the most disabled thalidomide babies in Britain. His plight became a cause célèbre, but Spanish thalidomiders are only now beginning to understand their own history.

"The Franco dictatorship kept us hidden and democracy has forgotten us," says Riquelme. "No one, including our present government, has wanted to see or hear."

Riquelme formed Avite in 2003 to campaign for recognition and compensation and, since 2008, under mounting pressure, the government has grudgingly recognised 23 cases — those whose mothers kept their prescriptions. They received a one-off payment in 2011 of between €30,000 and €100,000, depending on their disability — about one-tenth of the average award for other national schemes. That scheme is now closed.

Mariano Iparragirre didn't receive any compensation. His mother, Lierni, doesn't remember the name of the medicine she took to stop her morning sickness. The family has checked with the Basque health authorities, but were told all her medical records were destroyed in the severe floods that devastated San Sebastian in 1983. With no paper trail, it's impossible to prove that Mariano's disabilities were caused by thalidomide. But his mother is sure. "Here in Spain, they stopped importing it," she says. "But not selling it."

With great difficulty, when Mariano was four, Lierni found a physical therapist who taught him "how to take a piss, how to shower, how to eat, how to dress". She didn't let him use his feet, as a lot of thalidomide children in England were taught to do because, who writes with their feet? Mariano, now a draughtsman, learnt to write using his one finger, supporting a pen with the stump of his left arm. He had 13 operations between the ages of 5 and 12 to extend his grossly foreshortened right leg by 35cm so he can walk without a prosthetic.

Mariano's wife, also called Lierni, who speaks a little English, tells Mariano's story while her mother-in-law looks miserably uncomfortable. She cradles her grandchild, Mariano's sleeping daughter, Mara, a perfect one-year-old with eyelashes so thick and dark they look as though they have been drawn on. Occasionally, she adds a word or two, but she doesn't look at me: "My love for him was special," she says. "Tell her I tried to find him the best help I could."

Claus Knapp, one of the doctors who lifted the lid on thalidomide in Germany 54 years ago, moved to Spain in 1963 and now lives with his wife in Madrid. "I was told there were no cases here," he says. "Only now are we beginning to discover it's the worst-affected country in the world." On his kitchen table, Knapp spreads out the original charts he and a colleague, Widukind Lenz, made in Hamburg in 1961. Names, pregnancy dates and the days



Analia Muñoz, 31

they took Contergan, the German brand name for thalidomide, are meticulously plotted on tracing paper. One pill was enough. If women took it on day 30-35, their child had no legs; day 24-28, the child had reduced arms. One mother swore she hadn't taken anything. But she'd had an appendectomy, so Knapp broke into the hospital archives and went through her records, and there it was: thalidomide.

During the telling of this story, he drops the teapot he's holding and it crashes to the floor. "We were poor, I had a little car, but Lenz only had a bike. I worked every night." They started on November 1, 1961, and by November 17 they knew what was causing the deformities. "Truthfully, they were the most intense 17 days of my life."

Knapp knows what it is like to take on Grünenthal: following their discovery, the pharmaceutical giant set private detectives on them. It threatened legal action, it even tried to discredit the mothers who came forward, but on November 27, 1961, under pressure from the German press and department of health, it capitulated and the drug was taken off the German market. Britain and the rest of the world quickly followed, but not Spain.

Import documents show that, between 1960 and 1962, Grünenthal sent 439.05kg of raw product to Spain — enough for 17.5m 25mg pills — and applied for and was granted

licences for 10 different products. Around 4m doses of Softenon, marketed as a sleeping tonic — "completely natural and safe" — were sold all over Spain from 1957 to 1963. Insonid 10, registered in three different strengths on July 11, 1959, was not withdrawn until July 1969. Entero-sediv was officially withdrawn in Spain in December 1962 — a full year after it had been removed from the market in other parts of the world. But Spain's prescribing and clinical reference directory, Vademecum Internacional, continued to carry it right up until 1975. *Talidomida* is no longer listed as an ingredient, but since doctors were never warned of the dangers, they would presumably have continued to use up their stocks. Avite's Rafael Basterrechea believes the product never changed. He shows me the packaging from a packet of Entero-sediv tablets from 1975, which still has *talidomida* marked on the box.

The doctor who delivered Esther Fernandez on April 27, 1966 — nearly five years after Grünenthal withdrew thalidomide from sale — told her mother: "You have seven other children. Let this one go, she will only cause you pain and trouble." Esther was born with short arms and one stump of a leg. She wears a prosthetic, which means a tiny, distorted foot perches on a shelf where her knee should be. She wriggles her toes. She's not remotely self-conscious. "I cried a lot, >>>→

"You write that you will not disclose the reason for the sales ban to the Spanish doctors," Grünenthal wrote to its sister company in Madrid in 1961, adding: "We concur"

but I've worked hard to understand who I am," she says. "I'm a very strong, beautiful woman. I love me!" Can I feel your leg? I ask. It's soft and boneless, like a melon. "Now can I feel yours?" she says, laughing.

The doctor who visited the village weekly gave her mother, pregnant and working in the fields, something from his bag to combat her exhaustion. No prescription? She throws up her hands. "It's very important you understand how people in Spain lived," she says. "We washed our clothes in the river and slept in the same house as the mules and pigs. The Franco regime was something you breathed in. You had the priest, the civil guard, the doctor. They were a team, lined up in authority. There wasn't such a thing as a medical error."

Teresa Nebreda called her second son, born limbless and without ears, on May 8, 1985, Angel — "Because he looked like an angel," she says. At his birth, doctors told her: "This is a thalidomide baby." She says: "I decided at that moment I will not be crushed by this." Her love for Angel is special and ferocious. "He was the most precious child in the world. He had the most kisses, the most love. Angel was funny and clever and so motivated. When we went to the supermarket he'd carry sugar between his shoulder and his cheek. He was a happy boy and my life was built around him, my arms were his arms." Angel died, aged 8, on June 11, 1993, of pneumonia. "I am Avite Member 15 — in memoriam," she says. "I want some justice for the survivors. But Angel was never a burden. It has been much harder to live with his death than his birth."

In 2013 Avite took civil action against Grünenthal and won. But in November last year, Grünenthal's lawyers succeeded in getting the judgment reversed on the grounds the victims sued too late. Ignacio Martinez, Avite's exhausted lawyer, is preparing to take the case to Spain's supreme court. "Stalling works well for Grünenthal," he says. "Many victims now suffer poor health. In the last few years, 17 members of Avite have died."

In Germany, the *Conterganstiftung* (the post-trial settlement from Grünenthal of DM100m for those who took Contergan) ran out years ago. The company was granted immunity from criminal prosecution and it has never paid any more, nor has it accepted responsibility. Now the British National

Advisory Council is petitioning the German chancellor, Angela Merkel, to meet the increasing financial needs of victims in Britain and across Europe, many of whom are suffering failing health. The campaigners have secured a meeting with the president of the European parliament, Martin Schulz, this Tuesday.

Wherever the NAC goes in Europe, people listen. They bang on doors and storm meetings, carrying their briefcases on shortened arms, well aware of the discomfort and furore they are causing. Nick Dobrik, the NAC chair and campaign leader, expects it will only be a matter of time before Merkel capitulates.

"The Spanish story is truly awful and despicable," he fumes. "The actions of Grünenthal can't be adequately described by the word 'criminal'. They were self-evidentially evil. We do not understand how the German government, who had all this information, failed to share its knowledge with fellow governments and the medical community. They must now make a fair contribution to the health needs and independent living costs of thalidomide survivors in Denmark, Finland, Italy, Spain, Sweden and the UK."

Having kept thalidomide hidden for so long, the Spanish government now faces the task of differentiating thalidomide victims from those born with congenital limb-reduction deficiencies (around 50 in every 100,000 live births). Last year, the World Health Organisation revised its report on thalidomide embryopathy, identifying and clarifying classic thalidomide features. And St George's Hospital in Tooting is in the process of developing an algorithm to aid diagnosis, but the Spanish government has consistently refused expert help.

A one-armed Avite member I met, who may or may not be a thalidomide victim, showed me a letter he'd received from the department of health, saying: "Your mother must have fallen, or maybe she smoked or drank" — an unhelpful, unscientific response that just adds to the information vacuum Spain is under increasing pressure to address. While politicians play for time, families bear the brunt of caring and carry the financial burden.

Analia Muñoz, 31, lives in Granada with her parents, Antonio, 63, a plumber, who has adapted their home for her, and Ana Maria,

60. When Analia was born in 1983 with short arms and legs, no ankles or hip joints, no ears, a cleft palate and facial deformities and paralysis, doctors said her mother must have caught a virus. Ana Maria remembers being given an injection and some pills during a visit to hospital when she was three months pregnant or less, but the hospital records have disappeared.

Analia says she had a bad time at school. "I was always hiding my hands so people couldn't see them. No one wanted to work with me." She loved maths, she says, "but I took so long to get from class to class, I gave up. No one helped me." She's done a secretarial course at home and studied to be a tourist guide. She was once offered a job, but she couldn't do it as she needs someone to help with personal care — washing, showering, going to the loo. Mum does it all. So no, she has never worked. The economic crisis has hit the family hard. Antonio gets a bit of plumbing work, but Analia's only income is €250 (£185) a month disability benefit. "The friends I had have paired off and got married," she says. "I'm frightened when my parents go I'll be alone."

It's impossible to prove conclusively that thalidomide caused Analia's injuries, but no one could say that the drug was properly withdrawn from the Spanish market. The names roll down the decades. Francisco Gonzalez, who has short arms, was born in 1957; Jesus Marco, no arms, 1961; Luisa Torrijo, short arms, 1963; Esther, 1966; Jose Plasencia, no arms, 1971; Sofia Garcia, no arms or legs, 1974; Mariano, 1976; Analia, 1983; Angel, 1985. "These are our people," Claus Knapp says firmly, looking at the images. "And I am the last person to testify."

For the first 26 years of Mariano's life, his mum looked after him, then his wife Lierni. "One month after I met him at work, I fell in love," she says. "When I told my mum, the first thing she said was: 'How does he wash and dress and clean his arse? If you have children how will he take care of them?' I didn't care, I just wanted to be with him. Mariano rarely asks for help, but it is really hard. He can't hold the children, he can't bathe them, he can't dress them. We have no help at home so when I'm not there, his mum has to be."

Mariano's mum is 76 now, and at the house every day. "Not just because she loves him," says Lierni, "but because she feels guilty." But what happened to Mariano wasn't her fault. "Of course, but she feels it. That's why it's so important not just to get a financial settlement, but acknowledgement. Until then, this is her job. Her lifelong legacy. 'I did this to my boy, so it's my job for ever and ever to be there to help him.'" ■

“Stalling works well for Grünenthal,” says Ignacio Martinez, the Spanish victims’ exhausted lawyer. “Many now suffer from poor health. In the last few years, 17 of them have died”

Attacking the Devil

Watch an exclusive clip from *Attacking the Devil*, a documentary out in September on the original landmark Sunday Times campaign **On tablet, or at thesundaytimes.co.uk/thalidomide**