

Porto ●●, November 15, 2019.

Dear Sirs,

I was born on June ●●/1962, in a planned pregnancy, as the second daughter of a young couple. Because of my mother's nausea, the family physician prescribed the drug SEDALIS that had been widely marketed for this purpose. There were only three pills, but at the wrong gestational time - at the beginning of pregnancy, when my body was being formed. In the final months of my pregnancy, my father read in the newspaper that babies were being born defective in Europe due to the drug Thalidomide, but said nothing to my mother. She, in turn, also read in a magazine, and naively clipped the news and sewed on the hem of a dress so that my father would not know. Finally, on the Sunday that Brazil won the World Cup in Chile, I was born. A chunky baby girl with focomelia: shortening of the arms, without forearms, and malformed hands, with four fingers in each hand. I had read that at the time of the spread of this world tragedy (first reports in 1957/1959 and in three years, more than 10,000 affected children worldwide), legal abortion was released in Sweden, and there were even cases of mothers who killed their babies. I don't know how my parents initially faced this situation, but I'm sure they really wanted me, nurtured me, and made me grow up in a loving, stimulating and positive environment - I was raised just like my other three brothers, without any restrictions due to my physical limitations.

The history of thalidomide in Brazil was different from that of other countries. Its commercialization began in March 1958, almost two years after the identification of adverse effects in Germany. It first appeared as Sedalis, a drug advertised in three major newspapers in 1959 and aimed at the "Distinguished Medical Class", where the Pinheiros Institute, Therapeutic Products SA in accordance with Germany's "Chemie Grünenthal", launched the drug (with large free samples and literature distribution). Over the years it has been used under the trade names SEDALIS, SEDALIS 100, SEDIN, and SLIP - and finally, newspapers brought their readers in 1962 numerous accounts of the thalidomide tragedy in the world, highlighting the scientific aspects of the phenomenon, with an emphasis on question of its effects on the body of affected babies. In a newspaper of the time, cases of thalidomide embryopathy were reported under the headline "Sedative

made small monsters" and questioned drug safety: "Thousands of little 'monsters', victims of congenital deformities, are present today in several countries in the world - terrible warning about the unknown dangers of modern miracle drugs". Initial notes on thalidomide withdrawal were given by the Official Gazette and the newspaper O Estado de S. Paulo in August 1962 - at that time the number of 300 affected Brazilian babies was estimated. However, the drug was suspended only in 1965, at least four years behind Germany, as reported by the media. Even after the official withdrawal, thalidomide remained in some drugstores in the country, still allowing its use in unsuspecting pregnant women.

In the 1970s, Brazilian newspapers began reporting financial compensation for thalidomide victims around the world, and my mother (who had become a widow), asked the help of a close Brazilian friend who lived in Germany. So, we started proceedings with the Federal Ministry Germany, who referred me for inclusion in the group of victims on trial at the time. After the trial, I was invited to Germany to investigate the extent of thalidomide's damage. I was examined by Prof. Dr. Marquardt in Heidelberg (officially nominated by the German government to assess thalidomide damage). The causal relationship between damage and thalidomide intake was clearly established and I was included in the German Thalidomide Victims group in 1974.

Currently 57 years old, I have university degree, I am a well recognized professional and I work a lot. Even though, despite being functionally efficient, I have a physical disability with orthopedic deformities in the arms, hands and spine that cause me periodic pain, difficulties to perform some movements and limitations to perform some activities of daily practice. Not to mention that these deformities have occasioned situations of moral and social constraint on several occasions. In addition I have a partial deafness, I have had balance disorders, and despite having a healthy daughter, I have had several gestational losses related to the late discovery of a bicornuate uterus - malformation also associated with thalidomide. As I reported earlier, I was raised in a loving and inclusive family, but I could have developed emotional trauma and various psychological issues related to the pressures of living in a world where physical perfection is highly valued.

Very recently - less than two weeks ago - I received a letter from the Conterganstiftung Foundation informing me that I would be dismissed from Payment of Lifetime Compensation that was approved in 1974. Conterganstiftung justified by the fact that, when evaluating the documents in my dossier, they found that my mother took the drug SEDALIS, which according to the new rules of the Foundation was not produced by the Chimie Grünenthal. The same is happening to nearly one hundred people affected by Thalidomide in Brazil as we have all been affected by ingesting commercial forms that only existed in Brazil.

I bring this issue up because I consider this a second scandal involving Thalidomide - the first one occurred in the early 60's when thousands of children were born with multiple malformations - serious consequences of the negligence, greed, disrespect and total recklessness of a pharmaceutical industry. The second scandal now happens in Brazil, in 2019, when this Foundation creates new arbitrary rules and disrespects court decisions. And what it is doing to the affected people in Brazil is a crime of discrimination of national origin (to us, foreigners of the German nation) - since in our country products manufactured by Chimie Grünenthal certainly have different trade names from those produced originally in Germany.

In fact I have always found the name of "Thalidomide Victims" a bit annoying, as I never considered myself a victim of anything. However, given the current juncture, I am really finding myself a victim of the teratogenic effect of a drug taken by my mother; a victim of the greed of the German pharmaceutical industry CHIMIE GRÜNENTHAL who made a mistake by not adequately testing a drug and continued to produce and to market it even knowing its damages; a victim of iatrogenic acts committed by physicians who prescribed drugs offered in lay newspaper advertisements; a victim of civil society who dared to call us (and sometimes even today) as "little monsters"; a victim of countless children, teenagers and adults who cross/crossed me in the streets and look away making me feel a freak of nature; and finally, a victim of the recent decisions of the Conterganstiftung Foundation who are forgetting that we, Thalidomide drug affected people in Brazil, still pay a very high bill for the mistake made by Chimie Grünenthal / Contergan.

I conclude this document by recalling a Canadian article I recently read that stated that this lifetime indemnity should also be

paid to our mothers. I completely agree because I cannot imagine the fears, fantasies, anguishes, sadness, despair and guilt that each pregnant woman felt when discovered that has received Thalidomide ("the damn medicine" - as called by the press at the time). Can we imagine how they felt seeing their long-awaited newborn with multiple malformations? Also, imagine the doubts about this child's future (uncertainty of how the kids would turn in life). I am well aware of this pain when I observe that my mother, 89 years-old, still fills her eyes with tears as she observes that someone stares at me with some strangeness.

I hope the German government and the Conterganstiftung Foundation will support us and reevaluate their actions, and not make Thalidomide a new nightmare for so many Brazilians victims.

PAULA ●●

Thalidomide Victim Since 1962

Medical Doctor - ●●●●