



No Hand To Hold & No Legs To Dance On

by Louise Medus



a thalidomide survivor's story

Published by Accent Press Ltd – 2009

ISBN 9781906373573

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Printed and bound in the UK

Cover Design by Red Dot Design

Cover photograph by Darryl Corner

Other photographs: author's collection

For Emma, Jack, Darren and my mum and dad.

Preface

THE ASTONISHING STORY OF thalidomide must surely be the worst medical disaster in history: a pill which caused devastating birth defects even if a pregnant woman took it only once. A pill which was aggressively marketed as “completely safe” and particularly suited to treat nausea or sleeplessness in expectant mothers without any research being done to support those claims. Looking back from a modern perspective when health and safety standards are so rigorous, partly as a result of the thalidomide disaster, it seems almost unbelievable, the stuff of science fiction.

It was hard, cruel fact, however, and its savage effects had to be borne by thousands of children and their families across the world. Thalidomide was a phenomenally successful drug – by the time it was banned 64 million tablets had been sold – and it resulted in an epidemic of babies born with shortened, flipper-like limbs in place of their arms and legs. What is less well known because it is less visible is that the limb damage was only part of the story. Some babies suffered brain damage or impairment to their eyes, ears and internal organs or facial paralysis, conditions which could be even harder to deal with than limb reduction. In all cases the babies’ entry into the world, born to parents eagerly looking forward to meeting their beautiful new baby, was greeted by a range of the deepest emotions: profound shock, heart-rending pity or, sometimes, appalled horror.

Some parents screamed when they first set eyes on their thalidomide child. Fathers fainted dead away. Nurses were

sometimes so overwhelmed by the enormity of the task of breaking the news that they kept the babies wrapped and the parents only discovered the truth when they got home. There were stories of parents finding it impossible to cope and abandoning their babies; of fathers declaring that if their wives brought that “monster” home, they were leaving – and of some carrying out the threat; of couples doing their parental duty but only with great difficulty. Yet for all those who reacted with horror, there were far more parents who were flooded with a tide of love and protectiveness towards their helpless offspring and who brought them up to make the most of life. As for the babies, some were so deformed internally they died soon after birth but those who survived for the most part tackled life with gusto.

Many of the most severely afflicted, lacking all four limbs, were told they were not likely to survive childhood, then that they would die before they were 21, or 30, or 40. Now the “Thalidomiders”, as they call themselves, are all approaching their 50s and leading full lives; they have worked, brought up children. In short they have lives packed with the same rich range of joys and sorrows as anyone else.

Their amazing and humbling achievements have been accomplished against a backdrop of the massive changes in attitudes towards the disabled in society which has taken place since the early 60s. Disabled people used to be pitied, feared and shut away from sight in big institutions, but all that has undergone a revolution. With the help of modern technology they have come out from behind closed doors and now mostly live independent lives, contributing their own unique talents and energies to the benefit of society. They accept themselves as they are and make the most of what they have and in general society has come round to accepting them.

So how did a drug with such appalling consequences for the developing foetus ever come to be put on the open market? Until now the accepted wisdom has been that the manufacturers could not have predicted that it would cause birth defects but new research, currently being undertaken by the Thalidomide Trust, may result in allegations of criminal

negligence.

In the post-war era of the 1950s, science and invention seemed to be delivering a brave new world of nothing but good things. It was a time when almost every home began to acquire a washing machine, a refrigerator and a television, when computers were being developed and space travel began. In the world of medicine, the increasing use of penicillin in the 1940s was followed by a race to find new antibiotics, hailed as the miracle cure for the deadliest diseases known to man.

It was also when the first mood-altering drugs to receive the stamp of medical legitimacy were produced. Tranquilizers and sleeping pills – the “mother’s little helpers” of the time – became widespread. In Britain around a million people used some kind of sedative daily in the mid-50s and around one in eight of National Health Service prescriptions were for sleeping pills. The problem was that most tranquilizers were dangerous barbiturates and deaths from deliberate and accidental overdoses were rising alarmingly.

A company called Chemie Grunenthal, a sister company of a large, family-owned cosmetics company in Stolberg, near Aachen, West Germany, was trying to develop new drugs to take advantage of the rapidly expanding sedative market. According to the account in *Dark Remedy*, by Rock Brynner and Trent Stephens, the company’s director of research and development, Dr Heinrich Muckter, a former medical scientist in the German army, worked with the chief of chemical research, Wilhelm Kunz, mixing organic compounds to find something with pharmacological potential. Kunz, a former army sergeant, had been given his position despite having little scientific background.

Some time in early 1954, so the account goes, Kunz heated a chemical called phthaloylisoglutamine which changed its molecular structure. He and Muckter gave the drug that resulted the name thalidomide then looked around for a condition that it could cure. This may seem a curious way of doing things to the layman but was pretty standard procedure amongst drug manufacturers at the time.

Initial trials were disappointing as the drug had little effect

on animals, not even acting as a sedative. But the researchers were excited by the observation that it appeared to be completely non-toxic: even at extremely high doses, it did not kill rats. Muckter therefore authorised the company's pharmacologist, Dr Herbert Keller, to try it as a sedative for humans. Instead of conducting proper, controlled trials, however, the company simply distributed free samples through doctors and handed out pills to their employees, without any monitoring or follow up. One observer commented: "Thalidomide was introduced by the method of Russian roulette. Practically nothing was known about the drug at the time of its marketing."

The result was that the first thalidomide baby, a little girl with no ears, was born on Christmas Day, 1956, the daughter of an employee of the company who had taken home some of these samples when his wife complained of morning sickness early in her pregnancy. No one had an inkling of the connection at the time and the human trials were showing that thalidomide induced a hypnotic, deeply relaxed sleep. Many physicians were impressed and Grunenthal was so excited by its potential that on October 1, 1957 they launched it, under the patent name Contergan, without prescription, with an enormous publicity campaign including 250,000 personal letters to doctors calling it a "wonder" remedy, perfectly safe and with no side effects. Success was immediate and widespread: by 1961, thalidomide was the best-selling sedative in Germany, sales represented half the company's income and their staff numbers had tripled.

In July, 1957 the giant Distillers company, best known for manufacturing alcoholic drinks, acquired the rights to market the drug in the UK and throughout the British Commonwealth. So eager was the company to get the drug on the market it accepted a licence deal which allowed no time to do its own trials and it began distributing thalidomide under its own trade name, Distaval, in April, 1958. The drug was advertised as "completely safe," the ideal solution to the "mounting toll of barbiturate deaths". Eventually thalidomide was sold in 46 countries under at least 37 names. In August,

1958 Grunenthal wrote to German physicians declaring that thalidomide was the best drug for pregnant and nursing mothers, a claim copied on the Distaval label by Distillers without any scientific foundation.

Grunenthal and the other companies around the world persisted in aggressively pursuing this line of marketing despite the fact that there *were*, in reality, complaints from patients of side effects from early on. By the end of 1958 some physicians in Germany were reporting to Grunenthal that certain patients taking Contergan suffered dizziness, cold hands, feet turning numb, memory loss, trembling, constipation and decreased blood pressure. In October, 1959 a Dusseldorf neurologist called Dr Ralf Voss wrote asking the company if anyone had reported that their wonder drug caused polyneuritis – a numbness and tingling in the hands and feet which was affecting one of his patients. Heinrich Muckter and Gunther Sievers from the company replied that they had received no complaints of that nature, which was a deliberate lie. In fact, by the end of 1960 the company had received around 100 reports of nerve damage attributable to thalidomide.

Voss continued to suspect Contergan and in April, 1960 he reported to a conference of neurologists in Dusseldorf about three patients who had developed the nerve damage condition, polyneuritis – also called peripheral neuritis or neuropathy – after using the drug. Monitoring his patients over the following year, he never saw any of them recover their lost feeling – the damage done by thalidomide seemed to be permanent. Soon his voice was joined by others, including some British doctors. Pressure grew on Grunenthal at least to put thalidomide under prescription and some German hospitals banned it. But the company never ordered further research in response to these reports; instead it did its best to discredit them, cover them up and create confusion so it could continue to rake in huge profits.

Meanwhile, babies with severe and shocking birth defects were being born across Germany. The first one to be recorded as a case history was in December, 1959 when a Dr Weidenbach described a girl whose arms and legs were so

shortened that her hands and feet were attached directly to her body. The condition is called “tetra phocomelia”, literally “four seal’s limbs”, and occurs naturally in an estimated one in four million births. Other doctors who were seeing similar babies each thought it was a one-off, a sad but very rare genetic malfunction. At the same time in Britain, Distillers were sending out promotional leaflets about Distaval to physicians with no mention of the problems with polyneuritis and announcing boldly: “Distaval can be given with complete safety to pregnant women and nursing mothers without adverse effect on mother or child.”

On the other side of the world, however, the link was being made. Three women patients of Dr William McBride, who ran one of the largest obstetrics practices in Australia, gave birth within a month to babies with remarkably similar defects including missing bones in the forehead and blocked bowels, all of whom died. After the third death Dr McBride made a thorough study of his patients’ hospital records and discovered the one common denominator was that the mothers had taken Distaval in pregnancy. He was convinced that was the cause. As soon as he could, he phoned Distillers and told a representative of his conclusions. He always subsequently insisted that he also sent a paper to the British medical journal *The Lancet*, but the journal unfortunately has no record of receiving it. This was in June, 1961 around four months before a beautiful young pregnant woman in London called Vicki Mason was to take Distaval to help her sleep. Had that paper been published, much suffering would have been prevented and her daughter, Louise, would have had a very different life.

By the end of 1961 the connection was made in Germany, too. A young lawyer called Karl Schulte-Hillen had both a daughter and niece born with phocomelia and had sought an explanation from Professor Widukind Lenz, head of the children’s clinic at Hamburg University, who had already been sent details of a similar case. Astonished at this cluster of what were usually extremely rare defects, the pair put adverts in newspapers appealing for information about other cases and

Lenz began painstakingly trawling through the city's birth records and contacting the mothers of similarly disabled children. In subsequent interviews, one of the mothers mentioned taking Contergan during pregnancy; by November he had come across 14 cases where thalidomide was a common factor. He called Dr Muckter at Grunenthal and told him that Contergan should be withdrawn immediately. He said that every day the drug remained on the market was a deliberate experiment in human teratology.

In Australia, also in November, 1961, Dr McBride wrote again to the *Lancet* and this time his paper was published. In Germany, Professor Lenz told other physicians he believed Contergan was responsible for the epidemic of birth defects and met Grunenthal representatives at the Ministry of Interior where officials ordered the company to withdraw the drug from sale or they would ban it. Grunenthal refused, resisted all pressure and sent out another 70,000 leaflets to doctors insisting "Contergan is safe" until a major newspaper, *Welt am Sonntag*, broke the news of Lenz's findings on November 26, 1961. They cited his letter to Grunenthal which said: "Every month's delay in clarification means that fifty to one hundred horribly mutilated children will be born."

Grunenthal then had no alternative but to withdraw thalidomide from the German market and within a week Distillers followed suit. No one knows exactly how many thalidomide babies were born but current estimates put the figure at 15-20,000 of which perhaps a third did not survive beyond their early teens. There were nearly 3,000 known victims in Germany and over 650 in the UK. Even today some are still coming forward.

So, with the damage finally having been halted, the time came for the accounting. In May, 1968 nine Grunenthal executives were put on trial – one of the prosecutors was Karl Schulte-Hillen. The case dragged agonisingly on for two and a half years until the company claimed it could go bankrupt, leaving no money to compensate the victims, so proceedings were suspended "in the public interest". Towards the end of 1970, the West German parents accepted an offer of

\$31million which was topped up with a further \$13million by their government.

In Britain it took much longer, partly because after the first law suit was filed by 62 families against Distillers on November 7, 1962, the press was subject to a “gagging order” forbidding any mention of thalidomide while the case was being considered. After seven years of wrangling, the company offered an indecently small out-of-court settlement of an average £15,000 per child only to the 62 families in the original suit. To the rest they said they would pay £1,500 to each set of parents and set up a charitable trust of £3,750,000, the interest from which would be distributed amongst them annually. But there were two astonishingly draconian conditions – the offer must be kept confidential and it must be accepted by every single family: if only one refused to sign, no one would get a penny.

This condition acted like a red rag to a bull to wealthy London art dealer David Mason, whose daughter, Louise, was born with severely restricted arms and legs in 1962. At a mass meeting in London he and four other families courageously withstood the considerable pressure from the company, the lawyers for both sides and all the other parents present by refusing to sign to accept the offer. Furious at what he saw as immoral blackmail, Mason determined to take the fight to the press. *The Sunday Times* was already investigating the story but the first newspaper actually to take the bold step of defying the gagging order was the *Daily Mail* whose then editor, David English, was a friend of a friend of Mason’s. Though English risked going to prison, the paper published a story: “My Fight for Justice – by the Father of Heartbreak Girl Louise” on December 20, 1971. English was not arrested but it was almost a year later, in September, 1972, when *The Sunday Times*, under its campaigning editor Harry Evans, also mustered the courage to challenge the law by launching one of the most powerful and effective campaigns in British publishing history with a story entitled “Our Thalidomide Children: a National Shame”.

David Mason became the public face of the campaign for a settlement which would properly compensate the thalidomide

victims for loss of earnings during their lifetime and guarantee them a comfortable standard of living. Tall, good-looking and forceful, he was a charismatic campaigner who took every opportunity to appear on TV or radio and to give interviews to the press. Meanwhile Jack Ashley, a deaf Labour MP, began an impassioned campaign in the House of Commons and a group of ten concerned Distillers' shareholders recruited others, including some large companies, to demand the company act responsibly.

Under this relentless pressure, Distillers gradually increased their offer until in April, 1973 they finally came up with an acceptable package amounting to £26 million, including an element for inflation, and the Government then added an extra £5 million to offset any future tax liabilities – a total of almost ten times the amount that Distillers originally offered in settlement. A measure of how necessary this enormous campaign was is that victims of thalidomide in Spain and Italy have never received a penny in compensation because there has never been a public campaign to demand it.

The creation of thalidomide and the struggle to gain justice for its victims had a profound impact on the public's attitude to medicine – until then scientists and doctors had been trusted to know best and do things right. This was the first example of serious physical harm being done by a supposed medical advance. Afterwards the notion that a doctor is necessarily always right had gone for ever and the belief that scientific advances in medicine were exclusively for the good was shattered. Far more rigorous testing on animals, particularly primates, was introduced for new medicines, which has resulted in its own controversy over the ethics of using animals in research.

While this was going on the surviving thalidomide children grew up and tackled the problem of how to make a life for themselves, and on the whole it has been a remarkable success story. Most of them have done useful work, forged relationships and had families of their own. Fifty years after thalidomide went on the market they are now entering middle age and have launched a new fight to get additional funds to

pay for the appliances and adaptations they will need as age takes its toll.

This year David Mason's daughter, Louise Medus-Mansell, will be 47. Married last year for the second time, she has two children by her first marriage, does volunteer work she loves and plays a valuable part in her community, but it has not been an easy ride. Her story typifies the struggles many Thalidomiders have been through and the triumphs they have achieved.

While the compensation battle was raging in the 1970s, the MP Jack Ashley asked in a parliamentary debate how Louise, then 11 years old, could ever look forward to "laughing and loving with no hand to hold and no legs to dance on".

Well, says Louise, "I have danced. I have held hands with a lover. I have married and had my two wonderful children. I have worked, I have played, I have loved and been loved and I've been hurt. It's a full life, just like anyone else's but more precious to me in its ordinariness, perhaps, because that very normality has been a struggle to achieve."

This is her story.