DAMAGED

- thalidomide victims in medical documents

With these ten portraits Simone Mangos takes us to the edge of human endurance. The gross injuries inflicted may be described in words through many media. Simone Mangos has chosen the visual image to best tell these stories of the suffering body and each person's courageous tenacity holding to life. Their portrayal may shock in its realism, but that reality respects the integrity of each suffering individual. These things should be known so that we can better take care.

Fifty years ago, in November 1961 two doctors, one in Germany, the other in Australia, observed the upsurge in severe deformities evident in newly born children. Their further inquiry linked the damage to the mothers' use of the drug thalidomide in early pregnancy. In Germany the late Dr Widukind Lenz wrote to Chemie Grunenthal, manufacturer and distributor of thalidomide. After some ten days of argument – and adverse reports in the press – Dr Lenz persuaded the company to withdraw the drug from the German market. After several more months it was withdrawn from elsewhere in Europe and countries in Asia, Africa and South America.

In Australia Dr William McBride made the same discovery and published his observations and analysis in a letter to the Lancet of 16 December 1961, Lenz and McBride corresponded and agreed on the coincidence of their detection of the teratogenic effects of thalidomide. The Australian distributor, the Distillers Company of the United Kingdom withdrew Distaval (thalidomide) from that market. McBride was widely honoured for his discovery – notably with a medal and prize money awarded by L' Institut de la Vie in France. The prize money he used to establish Foundation 41 for research into maternal and foetal welfare during the 41 weeks of pregnancy and first few days of life in the world. Other Australian honours, including the Order of Australia followed. But McBride's suspicion of pharmaceuticals used during pregnancy prompted him towards hasty research. He was and remains profoundly apprehensive of drugs used in pregnancy. He was a ready expert witness when damage to babies before birth led to claims for damages in U.S. courts and elsewhere. He was a crusader who made powerful enemies.

In 1954, a few years before this simultaneous discovery from distant ends of the world, the drug thalidomide had been synthesized in a research laboratory. The following year the Swiss research was acquired by a German pharmaceutical company for development and trial. Three years later, in 1957 thalidomide was being marketed around the world primarily as a sleeping pill and for the relief of nausea during early pregnancy. There is a long list of countries where thalidomide was readily available for this and other clinical uses. But not in the U.S.A. One woman, medical pharmacologist and reviewer for the Food and Drug Administration, Frances Kelsey opposed its sale. Her opposition won out and U.S. babies of that era were saved from thalidomide's disastrous impact. Elsewhere many thousands of babies died within the first year of life and more were damaged for life (It is calculated that over 10,000 victims survived to live with grotesque deformities), Many of that cohort of babies, born during the five years 1957 to 1962, who were injured in utero by thalidomide now live as a continuing warning of the fragility of prenatal life in the face of the uncaring haste to market

of major pharmaceutical companies. Thalidomide does relieve the symptoms of some diseases, but its use in pregnancy (for which it was sold) wreaked terrible and enduring damage.

Thalidomide taken early in pregnancy, between the third and sixth week gestation, interferes with the formation of limbs, ears and some internal organs. The affected baby may have grossly shortened arms or legs, or no limbs at all. Her ears may be missing with consequent deafness; face and eyes may be distorted by impaired facial muscles; damage to heart, bowel, gall bladder and uterus may bring lifelong illness. Some 40% of these babies died within their first year of life.

The survivors, now known as 'Thalidomiders' have sued the corporations held responsible for their injuries and fought long and hard for compensation to assist them to live with horrendous injury. In some countries that struggle has brought recognition of what they are owed. Some of the drug companies which manufactured or marketed thalidomide have contributed to trust funds for thalidomide victims. In Australia the law firm Slater & Gordon negotiated compensation from Diageo (the successor to the original British company that marketed thalidomide - trade-named Distaval). The award of $28.5 million held in trust should yield funds to be applied to giving some ease and care to the lives of surviving Thalidomiders. But the legal battle continues. In December 2011 Peter Gordon of Slater & Gordon opened a class action against Chemie Grunenthal, the inventor and manufacturer of thalidomide to be retailed world-wide under various trade names. The pharmaceutical 'knew or should have known' the possible damage to early foetal life. That action continues now.

This exhibition through ten compelling images tells the story of the injuries visited upon the children of mothers who took the drug during the years 1957 to 1962. For those who survived life has been lived in quiet desperation and demonstrable heroism.

Simone Mangos some years ago became aware of this population of sufferers entering middle age. She determined to bring them into view and to promote discussion of their fate.

Thalidomiders (the very name stigmatizes) were no longer small children evoking pity and empathy. They had aged, were seen as ugly, and were living in pain, often in poverty. Their plight, Mangos believed should be made visible.

She encountered defensive professionals and others who presided over the victims and decided 'what was best for them'. Her attempts to learn more from the survivors themselves were frustrated. She then turned for further insight into their lives to the clinical literature recording their deformities.

Mangos was disturbed by the frequently crude and forensic way in which the Thalidomiders as congenitally deformed children had been photographed and handled. Often the injured children were posed stark naked and held firmly, severely in place by unidentified persons. Other young people (teenage girls and boys) were photographed semi-naked from every angle to display their grotesque deformities. Background to the malformed body was often a makeshift room and a view of a useless prosthesis propped there for some inscrutable purpose. All sense of the human person was absent. They were curiosities. These were not individual human persons but rather specimens for the clinical gaze.

The Thalidomide Trust in the United Kingdom allowed Mangos access to their archives and, with the permission of the persons depicted she was given copies of some of their photographs. These form the basis for several oil paintings on show.

When these thalidomide sufferers allowed the artist to receive copies of their photographs, several people contacted her and spoke of their experiences. These were tales of distress and humiliation as the 'patient' was stripped, prodded, probed and discussed as if she were absent from the scene. The patient is exposed and recorded and the observers are largely anonymous and distant – beyond surveillance.

Given this privileged access to the ignominy of their plight Mangos looked for the most telling way to make known their sufferings. She has used the photographs as subjects for the oil paintings here exhibited. The focus is on the individual at the centre of it all, not on the pharmaceutical company. The large oil paintings have a monumentality and weight not to be dismissed. The plight of the subjects is a wide-world scandal – those afflicted come from many countries. They tell of a universal deprivation that is yet to be fully recognized. Here is suffering on a heroic scale. The artist confronts us with the pity of it all.

Much of the detail of that most grave scandal, the marketing of thalidomide has dropped from current imagination, but consciousness of the fragility of the unborn and their susceptibility to alien substances, including authorized drugs remains. If we stand in awe before these portraits of a suffering humanity we now recognize a certain grandeur of her crusade, Simone Mangos has given us something to think about.

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