

A 50-YEAR
BATTLE



THEY WERE BORN **FIGHTING**

Some thalidomide children were simply left to die. But many survived, even thrived, against the odds. Fifty years after the drug was forced off the market, **Marjorie Wallace** recalls the victims' courageous battle for justice. Interviews by **Caroline Scott**

PORTRAITS BY ZED NELSON
AND VINESH KUMARAN



IT HAD BEEN A CRUEL LOTTERY, SOME BABIES RESEMBLING JUMBLED JIGSAWS

BY MARJORIE WALLACE

Those were dark days when, as a young reporter newly recruited to the Insight team of The Sunday Times, I was sent to interview as many of the 466 thalidomide children and their families as I could track down. The children, then aged between 10 and 12, had been born with missing or foreshortened arms or legs. Some had horrific internal and external malformations. A few were blind, deaf or suffered brain damage.

It had been a cruel lottery, some of the babies resembling jumbled jigsaws. Such was the fear, secrecy and blame surrounding their births, many families found themselves shunned and isolated. Even at the time I met them, it was not always known or accepted that the children's deformities had been caused by a medication prescribed for morning sickness.

It was not easy to find the families and gain their trust. Yet their stories were vital to the Sunday Times campaign to force Distillers, the drug's British licensee, into providing adequate compensation, and to enable the paper to publish the true story of how the drug had been produced without adequate testing, and marketed some time after links between it and deformed children had been acknowledged. By this time, we were already in possession of damning internal pharmaceutical documents but, because two test cases for compensation were pending, publication of the story would have been contempt of court. The strategy, therefore, was to wage a moral rather than a legal battle and run a sympathy campaign — heartbreaking stories, week after week, describing the impact of the damage. In all, I interviewed 120 victims.

I will never forget the day Terry Wiles, a 2ft-high armless and legless torso, was thrust into my arms as we went into a

cafe and I watched the queues disappear. Similarly, when I went to a crowded beach with a family whose daughter had neither arms nor legs, an empty space soon appeared around us.

"To begin with, they were not expected to live," says Dr Claus Newman, a consultant paediatrician. "We believe that many were simply allowed to die." In some cases the midwives and nurses had been too afraid to tell the mother: one mother did not discover that her child had no arms until she unwrapped the shawl at home. Three mothers committed suicide. But it was the fathers who seemed the least able to take the sight of their misshapen child. "If you bring that monster home, I leave," said one. She did and he left. "If it weren't for you being so neurotic, I wouldn't have the son I have," said another. He also left, never to return. Dr Martin Johnson, who now heads the Thalidomide Trust, estimates that within those first 10 years of bringing up a thalidomide child, about half the marriages broke up, and even the strongest relationships were tested to the core.

The preoccupation of the medical profession at that time was to make the children look as normal as possible, which meant fitting them with artificial arms and legs and amputating extra fingers or grafting on a missing ear that would never function but looked more acceptable — all in an effort to "tidy them up". At Chailey Heritage, the home where a number of thalidomide victims were sent, I used to see children strapped into artificial legs like tin soldiers, wearily clinking from one leg to the other.



It was the children themselves who took over the story and transformed tragedy into triumph, often casting aside their artificial limbs. When I visited them as teenagers and young adults, I was astounded by the balletic skills and imaginative ways in which those fortunate enough to escape sensory or brain damage compensated for missing body parts.

The majority had received compensation monies — a result of the Sunday Times campaign — and



were able to have adaptations to their homes: clever gadgets, wheelchairs in which they would race around kamikaze-style, and, later, cars. More than two-thirds of the thalidomiders drive.

Neither I nor anyone else could have predicted the sheer resilience, willpower and ingenuity of this brave generation. I am sitting in the Ritz, invited to dinner by Guy Tweedy, one of a handful of self-made millionaires whose foreshortened arms were no impediment to business talent. He and fellow thalidomiders are fighting a new battle to help sufferers in other countries who received little or no compensation.

The majority of thalidomiders succeeded in living a relatively normal life, sustaining jobs. But there have been casualties. I will never forget Paul Chapman, then in his mid-twenties, whom I visited in the care home where he had been abandoned. "I don't worry about having no arms or legs," he told me, "just one of those things... one of those things." He died a few weeks later.

Some never escaped the effects of childhood abuse, physical, sexual and financial — the last of these not helped by the rows and rifts created in some families by the payment of compensation. Some families who had abandoned their children suddenly reappeared to take advantage of the funds, and some of the beneficiaries, forgetting the sacrifice made by their parents, evicted them from what had become their adapted homes.

It has been a humbling story to follow through the years. Excessive use of joints and muscles and the distorting ways the victims had to adapt are taking their toll. Many now face chronic musculoskeletal damage and pain. The thalidomiders worked hard to make society feel more comfortable — to prove that being a person is more than having a complete body. Yet again, they may be paying the price ■ *Marjorie Wallace is the founder and chief executive of the mental-health charity Sane*



FAMILY GUY
Kevin Donnellon with his girlfriend, Angela, and baby daughter, Daisy

KEVIN DONNELLON

The doctor who attended the difficult labour of Agnes Donnellon at a northern hospital on November 28, 1961, threw her apparently lifeless baby straight into a box under the delivery-room table. When, against the odds, Kevin drew breath, Agnes was advised to leave him in an institution and expect nothing.

Kevin, now 50, the fifth of Agnes's six children, meets me at the station in his electric wheelchair and we weave through leafy suburban streets to the flat he shares with his girlfriend Angela, and their 17-month-old daughter, Daisy. "My mother took me home and spoil me rotten," he says. "I suppose she felt guilty. An entire room in our house was dedicated to my train set. Later, she built a stupid bloody bar to stop me going to the pub, which I hated, because it was designed to keep me in."

While Kevin had a gang of mates at his secondary school who looked out for him, no

allowances were made for his disabilities. "Other than being excused gym, I was expected to do what everyone else did." He and another thalidomide victim, Theresa Smith, would take their lessons standing up on false legs, strapped to a classroom radiator to stop them falling over. "The legs were so heavy you were constantly toppling and with no arms, you couldn't break your fall. I broke my nose and knocked all my teeth out."

He failed all his O-levels for want of a typewriter — "My hand wasn't strong enough to write: after 10 minutes I was exhausted." But he says his disability really hit him when his mates started getting girlfriends. "I had the same feelings as any other teenage boy — I fancied loads of girls." He eventually lost his virginity at 16. "And I thought that was late."

Kevin's parents were among the first 62 families to settle with Distillers, in 1968 — a disaster. He received just £22,000 in compensation, left in the law courts until he was 21 and worth only £19,000 when he collected it. (All the victims now receive an income from the Thalidomide Trust, as well as from a

government fund). "I had no idea about money because everything had always been done for me. I pissed it up in two years, maybe less. I left home and went on a bender. I slept around, even paid for sex, I had escorts coming to my flat. And I threw myself into revolutionary politics."

His first job was working for a disabled advisory service for Sefton Council. "They wanted someone to give it credibility." But he still had no real independence. "I had to be pushed everywhere. Before I left home, I couldn't even dress myself."

He is now, unhappily, out of work. He has three-and-a-bit fingers on one hand and two on the other, he's able to hug his daughter — though, happily, not change a nappy — and he shunts around the flat very nimbly on his bottom. The thing that changed his life beyond all else is his Clos-o-Mat loo, "because nobody wants their partner wiping their bum".

Just after I leave, he's off to watch Everton play Arsenal. The only things he's self-conscious about are his perfectly formed feet. "They're normal. Big toe, four little toes... but I don't like people looking at them." ■

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'MY DAD'S FIRST REACTION TO THE NURSES — "YOU'RE NOT GOING TO LET HER LIVE?"'



THE DAMAGE DONE
Louise Medus-Mansell says she was raped at the home charged with her care. She married fellow thalidomide victim Darren Mansell (right) in 2008

LOUISE MEDUS-MANSELL

Louise Medus-Mansell's father, David Mason, an art dealer, was one of the key campaigners against Distillers: tall, good-looking, wealthy and ferociously driven, Mason called for an international boycott of its products, depressing share prices and forcing a settlement. Today, Louise barely speaks to her father. She mentions a falling-out over her second wedding (she married fellow thalidomider Darren Mansell in 2008), but the real reason is more complex. Raised with 22 other thalidomide children at Chailey Heritage, rather than at home with her younger brother and sisters, she feels she is forever the outsider.

David and Vicki Mason were just 22 and 21 when Louise was born — young, beautiful and fortunate, with what Louise describes as a "Posh and Becks" glamour. "They loved each other so, so much. I was their first child and they were expecting a beautiful baby, not me."

Vicki was kept heavily sedated after the birth on June 23, 1962, and didn't see her daughter for 10 days. "I had a flat, bridgeless nose, short boneless 'flipper' arms and feet, a livid birthmark from ear to ear and jaundice. My dad's first reaction when the nurses drew the

blanket back was: 'You're not going to let her live?'" The same night, Mason, in a rage, went banging on their GP's door at 4am to tell him his wife had given birth to "a girl with no arms and no legs". When the GP looked at his notes, he said: "My God, I gave her Distaval [a brand name for thalidomide]."

"If there had been a public warning when the drug was withdrawn in 1961," says Louise, "three-quarters of us wouldn't have been born like this." Louise was 17 days old when her parents took her to Chailey, and for the next 17 years she was part of a rough-tough gaggle of thalidomidiers who learnt to bury their feelings and fend for themselves. Sometimes her parents visited; mostly they were busy at home. She was bullied badly, especially during her father's campaign. "The other disabled kids were jealous of us because we knew what was wrong with us; they didn't."

At 13, she says, she was raped by an older resident. "Nobody acknowledged it happened. In those days, people had huge problems with the idea of disabled people having sex, let alone the concept of sexual violence." Her only experience of home life was a week's holiday three times a year, "which was so special, it felt like going to a beautiful hotel. I never let my mother out of my sight". When they asked

what she wanted for her birthday, she'd say: "All I want is to come home."

Did her parents just think they were doing the right thing? "When I had my own children [Emma, 24, and Jack, 20], the love I felt was so strong, I knew I couldn't have done it," she snaps. Then concedes: "They believed in doctors and they still do. When people said, 'Put her somewhere where she can be looked after and get on with your lives', that's what they did."

Louise, 49, now lives in a purpose-built house in Cheltenham with Darren and a massive German shepherd, Ajay. She's offhand with one of her two carers who brings me tea: "At Chailey, we learnt that anyone with two arms and two legs was there to help us." She talks warmly about the mother of her friend David Hogg, who, ignoring expert advice, took him home and lavished him with love and attention. "I was a rogue, I was naughty and attention-seeking. By the time I was 10, I didn't fit in with my own family because I didn't understand family values — nobody had ever taught me any."

More recently, she asked her father: "Knowing what you know now, would you do the same thing again?" He said: "Yes." "He said I wouldn't be who I am today if I'd been wrapped up in cotton wool at home." ■

**HE DID IT HIS WAY**

Terry Wiles, who lives in New Zealand with his wife Robyn, uses an electric wheelchair to get around. Below: in 1977, playing the keyboard with his feet



LEFT: VINESH KUMARAN/GETTY FOR STM. RIGHT: MARK ELLIDGE/TIMES

TERRY WILES

Terry Wiles was born on January 12, 1962. Physically, he was one of the most heavily damaged thalidomide children. He was missing an eye, and had deformed ears, no arms, and four digits on one “flipper” foot, five on the other and no pelvic girdle; the lower half of his body is contained by a pad of muscle.

But in every other way, Terry is a colossal human being. His story bumps along, punctuated by peals of laughter and unprintable nuggets of thalidomider gossip. Abandoned by his mother, he lived at Chailey Heritage in Sussex until he was six, when he was adopted by Len and Hazel Wiles. At 10, he became the subject of several films and a book by Marjorie Wallace — *On Giant’s Shoulders*. He was one of the first thalidomiders to attend mainstream school — a triumph at the time, but in reality, a miserable experience.

“The teachers used to make fun of me and the kids were rough little bastards,” he says. “When I was 16, my carer let them put me in a sack and drag me round the room. I’d been a confident child, but school destroyed me.” At home, the Wileses found it difficult to let

Terry grow up. “They drummed into me the idea that I could never live independently. I didn’t have teenage years. I didn’t go out, I didn’t get drunk, I didn’t have girlfriends. My mother was such a domineering person, she’d scare people away. And all my life, people have intimidated that I should be grateful. But they should have been grateful to me because I changed their lives!”

Terry points out an uncomfortable fact: that for many families of thalidomide children, the compensation money was like winning the lottery. (The 1978 Distillers settlement consisted of a payment of £6m, and another £14m over the next seven years, paid into the Thalidomide Trust, and added to since). “My money was pissed up against the wall by my mother, who was a compulsive spender. And I know that happened to countless others.”

Terry’s wife, Robyn, who he married 22 years ago, ruffles his hair. “I can’t understand how the children’s money wasn’t legally protected,” she says. She’s cagey about her own background, revealing only that she comes from “a wealthy, professional family”.

“I kid you not, when I met Terry 25 years ago, he was living in a dump. Nobody could have been better for him than Hazel and Len, but they gave no thought to his future.”

In 1980, the family emigrated to America, lured by a company who’d offered to build Len a workshop where he could concentrate on developing the “supercar” wheelchair he’d designed for Terry. “It never materialised.”

They went to Australia and, finally, New Zealand. It sounds brave stuff. “Unless you were actually living through it,” retorts Terry. “The relationship between me and mum was at rock bottom.” Len died in 1995. He last talked to Hazel several years ago. “She wanted to keep me in this bubble: Terry, Mum and Dad. But Terry didn’t want to be a scared child, he wanted to grow up.”

The income from the Thalidomide Trust has enabled Terry and Robyn to build “a sanctuary” near the sea in Papamoa, in the Bay of Plenty. Terry relies on Robyn for his care. “I need help going to the toilet, bathing and I can’t drive because my vision is so bad.” His biggest regret is not working. “I’m a trained counsellor, which was the best thing I ever did — I learnt some survival skills. But nobody will employ me, because it’s easier not to. Quite honestly, nobody wants to be reminded of disabilities like mine.” ■

ETERNAL INNOCENT

Dominic Galvin has an IQ of 146, but is totally reliant on his mother, Sadie. Below: one month's supply of Dominic's medication



Sadie's hands are raw from clawing at the soil in the garden outside, tamed to perfection by so many early-morning sessions. She does the shopping before Dominic is awake, sees nobody but the neighbours and the lady who comes to the house to do her hair.

Sadie has lost Dominic progressively. He has an IQ of 146 but can no longer do anything for himself. She bathes him, shaves him, sits him on the loo. He can't co-ordinate his limbs, he can't chew and he can't swallow. She purees his food and feeds it to him on a teaspoon, joking and chatting, trying at all costs to preserve his dignity. "Because Dominic is so

'BECAUSE HE IS SO HIGHLY INTELLIGENT HE CANNOT TOLERATE BEING PATRONISED'

SADIE AND DOMINIC GALVIN

Sadie Galvin remembers every step she took to the doctor's surgery. "It was a Wednesday, half-day closing. I nearly didn't go." And she recalls the words of the chemist who handed her the "wonder drug" she'd been prescribed for palpitations. He said: "I don't believe in miracles." "If I hadn't taken those steps, if I hadn't swallowed those pills, Dominic would not be like he is. I keep thinking, what if? What if?"

Sadie is a tiny, sinewy 85-year-old, who looks as though she is held together by fury and willpower alone. She rattles through the legion of professionals who've let them down over the years: hopeless doctors and callow, negligent social workers who failed to understand the extent of the central brain damage that has obliterated, by degrees,

Dominic's personality, Sadie's marriage and any chance of normal family life.

Dominic was born on June 15, 1959, with deformed hands and feet — the least of his problems, it turned out. Always hyperactive, when he was three he began having *petit mal* epileptic fits; shakes and convulsions which lasted an hour, many times a day. He never went to school and has never even been to a daycare centre for more than a few hours because nobody could manage him. When Dominic was 10, Sadie's husband, Joe, issued an ultimatum. "He said: 'It's either Dominic or me.' So he went." Sadie shrugs. "I gave Dominic life and I wouldn't put him away."

She sleeps next to Dominic and gets up at 5am every day to give him the first of the drugs that stabilise him. Then she cleans the house from top to bottom. "If we've had a bad day, I wipe it away. It didn't happen."



Dominic, 5ft 10in and heavily built, often knocks things over as he staggers about, but there are always flowers "to keep it looking as though there are no problems in our house".

highly intelligent, he cannot tolerate being patronised." His speech comes hard and fast, but is totally jumbled. He gets into terrible tempers. Most of the time he is stupified by the drugs which control his epilepsy.

Sadie leads me upstairs to see him. He lies motionless under white sheets in a bedroom that smells of clean laundry. He has grey hair and alabaster skin as pale as the statue of the Virgin Mary next to his bed. There's a chair full of teddy bears, and Sadie has laid out his clothes. A 52-year-old innocent who has never known a life outside these four walls. Sadie gazes on him with love and pride. Earlier, I'd asked if the money Dominic receives helps and she had thrown up her hands. "Now do you see?" she says. "Could money ever make up for what he's lost?" ■

Thalidomide 50 Years On, a reception, conference and art exhibition, is being held at the Park Plaza hotel, London SE1, May 25-26. For more information, contact: thalidomide50@yaboo.co.uk



To see a short film of a day in the life of Kevin Donnellon, visit thesundaytimes.co.uk/thalidomide

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