



**SUKESHI THAKKAR, 46,** fashion designer (left, with her mother, Rama): 'My mother comes from a very well-to-do family in Kampala. When I was born, there were all sorts of ideas to leave me in the jungle and tell her I hadn't survived. As a day girl at an English boarding school, I was a disabled Asian outsider. I didn't drink all day, so I wouldn't have to ask someone to help me go to the toilet. I got eight O-levels and three A-levels, but I couldn't go to university because I couldn't manage the travelling or live alone. I still feel angry. Every day, I wonder where I would be if this hadn't happened to me'

**CLAUDIA AND UDO SCHMIDT-HERTEVICH** (right) are the leaders of the world's biggest group of thalidomide survivors, in North Rhein-Westphalia, Germany. Claudia is a clinical psychologist and Udo works in graphic design



# SURVIVAL INSTINCT

**It is 50 years since thalidomide blighted the lives of thousands, leading to a Sunday Times campaign to help survivors. Caroline Scott reveals the moving stories of some of the Britons affected by the drug. The portraits are from a new exhibition by Kathryn Rennie**



The portrait-sitters on camera. Top: Sukeshi and her mother. Above: Udo (right) and Claudia. Below: Rosie



**ROSIE MORIARTY-SIMMONDS, 47** (main portrait), is a disability-issues consultant who lives in Cardiff with her husband, Steve – also a ‘thalidomider’ – and their son, James

**FRED DOVE** (top right) has worked for the BBC for nearly 20 years and is now a World Service presenter. Born in Germany, he has been a key figure in exposing the German government’s harsh treatment of its thalidomide survivors

**MONIKA ELSEMBERG, 48** (bottom right), is a teacher who lives in Cologne. She has long campaigned for German thalidomiders, and works closely with the International Congeran Thalidomide Alliance (ICTA) in the UK







**T**halidomide was marketed in the UK in 1958 as a treatment for insomnia and morning sickness. Found to be safe in animal trials, but never tested on humans, it was launched in 46 countries before its terrible legacy was revealed by The Sunday Times. The drug's German manufacturer, Grünenthal, received thousands of reports of its

effect on the developing foetus, yet consistently denied any link. By the time it was finally withdrawn in the early 1960s, it had killed 100,000 babies in the womb, and a further 10,000 were born severely disabled. The medical historian Hans Ruesch described "10,000 children – but probably many more – born throughout the world as phocomelics, deformed, some with fin-like hands grown directly onto the shoulders, with stunted or missing limbs, deformed eyes and ears, ingrown genitals, absence of a kidney or lung, a great many of them stillborn or dying shortly after birth. Parents under shock, mothers gone insane, »»»→

**SADIE GALVIN, 81 (with her son DOMINIC, 49):**

**'I had terrible nausea and palpitations – I didn't even know I was pregnant – and the doctor said, "There's this wonderful new drug just out..."' Dominic was born with deformed hands and feet; then, when he was three, he started having massive epileptic fits. Now he can't chew or swallow, and his speech is constantly in a jumble. He asked me recently, "Why would God do this to me?"'**



some of them driven to infanticide..." It is impossible to imagine how these parents managed; around half of the affected babies died during their first year of life, and those who survived received precious little help. Some were abandoned by parents too traumatised to cope, or sent to special boarding schools. They were issued with painful, ill-fitting false limbs to make them look more "normal", and well-meaning surgeons removed fingers and toes for cosmetic reasons, removing what little dexterity they had.

### **'Everyone assumed we'd be dead by the time we were 25. We're still here, but we're all falling to bits and we need more help'**

About 3,500 "thalidomiders" survive around the world, 457 in the UK. Depending on their disability, UK victims receive an average of £18,000 a year from Diageo (formerly Distillers), the UK licensee of thalidomide. But in Germany, where the drug was called Contergan, the original settlement from Grünenthal wasn't index-linked and ran out years ago. Despite the German government doubling its contribution,

victims still receive only around £7,000 each. In Italy, Spain and Austria, there is no payout at all.

Guy Tweedy and Nick Dobrik formed the International Contergan Thalidomide Alliance (ICTA) and are leading a worldwide campaign to win around a million euros over 10 years, index-linked, for each of the surviving victims, many of whom are now beginning to suffer new problems associated with their disabilities. They are a fearsomely independent bunch, raised to do what they can for themselves rather than ask for

help, but those who have relied on their mouths and teeth all their lives are beginning to suffer dental and cranial problems; the discs in their backs are crumbling and they are losing the use of overworked hands. "Everyone assumed we'd be dead by the time we were 25," says Tweedy, now 46. "We're still here, but we're all falling to bits and we need more help." Dobrik, a former accountant, is the figures man, while ➤➤➤ 41





**GUY TWEEDY, 46** (left), is a self-made businessman. ‘The shock to my mother was immense. I went to boarding school at seven and left with no qualifications, but I learnt to stand up for myself and fight back. Between the ages of 18 and 24, I applied for more than 1,000 jobs and wasn’t offered one of them’

**GEOFF ADAMS-SPINK, 46** (right), is age and disability correspondent for the BBC, and chair of the Thalidomide Trust’s National Advisory Council. This exhibition was an idea that grew out of his friendship with the artist Kathryn Rennie. ‘The idea was to remind people of our suffering and our battles but also our achievements, our conviction and our beauty’

**NICK DOBRIK, 49** (below left), founded the ICTA with Guy Tweedy. ‘I’m always the first to say that my disability hasn’t affected my life. The people I’m most concerned about are those who are much more severely disabled’



## ‘In April this year, thousands of survivors marched on the German embassy in London, and it was the most phenomenal experience’

Tweedy describes himself as someone “who knocks down doors till I get what I want”. All the thalidomiders have an almost holy reverence for the Harold Evans-era Sunday Times Insight team, who, when a derisory compensation sum was offered by Distillers in the late 1960s, took their story to the European Court of Human Rights, changing the law on contempt of court in the process. The first in a series of articles

appeared in September 1972, under the headline “Our Thalidomide Children: A Cause for National Shame”. It took nine months, and cost the newspaper thousands of pounds in legal fees and lost advertising revenue, but it led to a new compensation agreement with Distillers in 1975, a deal that has been updated several times since.

Marjorie Wallace, now head of the charity Sane, who wrote the original articles, has kept in touch

with many of the families. “When I first met the children at 9 and 10 years old, people believed they’d be in institutions for the rest of their lives,” she says. “If I took a child to a cafe, people would leave. They couldn’t bear to look at these armless, legless bodies. In April this year, thousands of survivors from all over the world marched on the German embassy in London, and it was the most phenomenal experience. I met the children and grandchildren of the children everyone had written off as a lost generation.” ■

*Thalidomide @ 50, an exhibition by the artist Kathryn Rennie, is at City Hall, London SE1, October 1-20*