

The **Thalidomide** Trust

Media pack

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The Thalidomide Trust

Thalidomide – Some Q&As

What is Thalidomide?

Thalidomide is a sedative that was created by the German pharmaceutical company, Chemie Grunenthal, in 1954. It was promoted as a 'wonder drug' to treat a range of conditions including headaches, insomnia and morning sickness in pregnant women.

Adverts emphasised the drug's safety using phrases such as 'non-toxic' and 'no known toxicity' and 'especially suitable for infants'. However, the drug caused serious defects in unborn babies born to pregnant women who took the drug during the first three months period of their pregnancy.

When was the first Thalidomide baby born?

The first Thalidomide-affected baby was born in Germany on 25 December 1956 to a Chemie Grunenthal employee.

How many babies were affected by Thalidomide?

It is difficult to find accurate figures on the number of babies born with Thalidomide damage as many were not carried full term. Some were still born or died very soon after birth. It is widely believed that as many as 100,000 babies were affected by the drug in total. It is generally estimated that over 10,000 babies were born worldwide and today fewer than 3,000 survive.

What sort of damage did Thalidomide cause to babies whose mothers took the drug?

Thalidomide created a range of disabilities in babies including shortening and absence of limbs, malformation of hands and digits, damage to ears and eyes, sensory impairment, facial disfigurement/palsy and damage to the brain, internal organs and skeletal structure.

How long did it take for the link between Thalidomide and birth defects to be identified and the drug taken off the market?

Throughout the years, babies have been born with disabilities which are similar to the disabilities caused by Thalidomide. For example genetic conditions such as Holt-Oram Syndrome and TARS syndrome affect the upper limbs; Poland's Syndrome affects the hands; and Talipes Equinovarus affects the foot and ankle. This is one of the reasons that the link between Thalidomide and the birth defects it caused was not made straight away.

Recent evidence shows that a number of reports saying that Thalidomide was damaging babies in the womb were ignored by Chemie Grunenthal. However the first time the link between Thalidomide and birth defects was made public was in a letter published in *The Lancet* from an Australian doctor, William McBride, in 1961. The drug was formally withdrawn by Chemie Grunenthal on 26 November 1961 and a few days later on 2 December 1961, Distillers, the UK distributors, followed suit.

When was Thalidomide available in the UK?

The drug was licensed in the UK from April 1958 until December 1961. It was distributed in the UK by the Distillers Company (Biochemicals) Ltd ('Distillers) under the brand name Distaval.

How many babies affected by Thalidomide in the UK are still alive today?

There are currently 465 people in the UK who were affected by Thalidomide and are beneficiaries of the Thalidomide Trust.

What sort of problems has their Thalidomide damage caused them?

Many babies born with Thalidomide damage have grown up to have fulfilling lives with partners, able-bodied children and jobs they enjoy. However years of having to compensate for their disabilities and use of their bodies in ways that they weren't designed for have taken their toll.

Research shows that Thalidomide-affected people experience significantly poorer physical health than people of similar ages in the general population, Two-thirds reported their physical health was the same or worse than the lowest 2% of the general population.

The key health problems that have been highlighted through research are:

- pain – often severe and/or continuous (which is experienced by more than 90% of the Thalidomide Trust's beneficiaries)
- reduced flexibility and mobility - in particular a reduced ability to reach, stretch, and bend which makes it difficult to undertake everyday tasks
- tingling and numbness – which for many people results in a loss of strength/grip
- poor mental and emotional health – including depression and anxiety.

Many Thalidomide-affected individuals rely on adapted vehicles, electronic wheelchairs, prosthetic limbs or specialised hearing aids/implants which are very expensive. Others have lost or seriously damaged their teeth by using them - instead of hands - to undertake a multitude of day to day tasks and now need expensive dental implants. It is also frequently necessary for them to adapt their homes to accommodate their disabilities.

Their Thalidomide-related disabilities have also impacted on their ability to work as they get older – with over 40% unable to work because of their disability or health problems and around a quarter having to change their job or the type of work they do for the same reason.

Do people born with Thalidomide damage have children with similar disabilities?

No. Many Thalidomide survivors have had children and, because their own disabilities do not have a genetic cause, they have not been passed on to future generations.

Did the people born in the UK with Thalidomide damage receive compensation?

Initially no compensation was paid. However, in February 1968, following a legal battle led by their families, compensation (at 40% of the level of assessed damages) was paid to 62 Thalidomide-affected children born in the UK by Distillers as a result of an initial (infant) settlement.

However this compensation was widely recognised as being completely inadequate and a high profile campaign was launched in 1972, led by the Sunday Times.

As a result, in 1973 a final settlement was agreed by Distillers. This includes a lump-sum payment for a further 367 children affected by Thalidomide in the UK (on the same basis as the initial 62) together with the establishment of the Thalidomide Trust to provide 'support and assistance' – including annual grants - to all Thalidomide survivors.

Since 2010, all beneficiaries of the Thalidomide Trust have also received a Health Grant from the Health Departments in all four nations of the UK to help meet the increased health needs caused by their Thalidomide damage.

What does the Thalidomide Trust do?

As well as administering annual grants to all their beneficiaries, the Thalidomide Trust provides information, advocacy and advice on health and broader wellbeing issues to support beneficiaries in maximising their health, independence and quality of life. An important role of the Trust is to support beneficiaries who lack the capacity to make decisions, to ensure that their needs are being appropriately met. The Trust also funds a small number of research projects in order to fill evidence gaps and develop increased understanding of the needs of its beneficiaries.

The Thalidomide Trust's Trustees and staff work closely with the National Advisory Council (NAC). This is a group of 12 beneficiaries elected by the beneficiary community, to ensure that the Trust is responding effectively to the needs of beneficiaries.

What do I do if I think I was affected by my mother taking Thalidomide when she was pregnant?

If you believe that you were damaged by your mother taking Thalidomide during her pregnancy, you can contact the Thalidomide Trust to find out if you are eligible for their support. Please note that

- In the UK, Thalidomide only affected people who would now be aged between 51 and 57.
- Certain patterns of disability are widely recognised as having been caused by Thalidomide. There are disabilities that look similar but have other causes. So even if you are aged between 51 and 57, your disabilities may not have been caused by Thalidomide.

If you fall within this age range, your mother was in the UK when she was pregnant, and you think you have thalidomide damage, you can apply to become a beneficiary of the UK Thalidomide Trust. The first step is to complete the 'Simple form' on our website and either post it to the Thalidomide Trust, 1 Eaton Court Road, Eaton Socon, St Neots, Cambridgeshire, PE19 8ER or email it to hello@thalidomidetrust.org. Your application will be assessed by a team of experts.

Is it true that the campaign to get proper compensation for Thalidomide survivors in the UK continues?

Yes. Although each person receives an annual grant from the Thalidomide Trust (funded by the initial Distiller's payment and additional funding from Diageo, the company formed in 1997 by a merger between Grand Metropolitan and Guinness - who took over Distillers in 1990) and a Government-funded Health Grant, Thalidomide survivors still have significant unmet health needs – and these are increasing as they age.

As a result, a group of UK Thalidomide survivors, led by members of the Thalidomide Trust's National Advisory Council (NAC) are currently campaigning to get the German government to acknowledge the role it played in the Thalidomide scandal and to address the funding gap that still exists. You can read more about their campaign here. <http://www.fiftyyearfight.org/>

Where can I find out more about Thalidomide in the UK ?

If you are interested in finding out more about the history of Thalidomide in the UK, you can contact the Thalidomide Society by email (info@thalidomidesociety.org) or by telephone (020 8464 9048) or you can visit their website: www.thalidomidesociety.org

Personal stories from UK Thalidomide survivors can be found on the Thalidomide Society's website through their oral history project. Please visit:

<https://soundcloud.com/wellcomelibrary/sets/thalidomide-an-oral-history>

The Thalidomide Trust

A Simple Timeline

- 1954 Thalidomide is created by Chemie Grunenthal, a German pharmaceutical company.
- 1956 25 December: The first Thalidomide-affected baby is born in Germany on to a Chemie Grunenthal employee.
- 1958 In April, Thalidomide is licensed for distribution in the UK, by Distillers Company (Biochemicals) Ltd ('Distillers'), under the brand name Distaval. The sedative was promoted as a 'wonder drug' to treat a range of conditions including headaches, insomnia and morning sickness in pregnant women – adverts emphasised the drug's safety using phrases such as 'non-toxic' and 'no known toxicity'.
- 1961 A letter is published in *The Lancet* from an Australian doctor, William McBride, for the first time publicly making the link between Thalidomide and birth defects.
- 26 November: the drug is formally withdrawn by Chemie Grunenthal in Germany. 2 December: Distillers, the UK distributor, follows suit.
- 1962 The Thalidomide Society is established in the UK by a group of parents of babies affected by Thalidomide.
- Writs are issued by families of 62 Thalidomide-affected babies born in the UK (within months of the deadline of 3 years from conception) to secure compensation
- 1968 A sum equivalent to 40% of assessed damages is awarded to the 62 Thalidomide-affected children from Distillers – the result of an initial (infant) settlement, following a legal battle led by their families with little or no media support.
- Chemie Grunenthal is brought to trial in Germany charged with intent to commit bodily harm and involuntary manslaughter.
- 1970 The trial against Chemie Grunenthal is brought to a premature end by the German government stating that the trial was 'not in the public interest'.
- 1972 A Sunday Times-led campaign is launched in the UK to secure a substantial level of compensation for Thalidomide-affected children in the UK.
- 1973 Building on the 1968 settlement, a final settlement is agreed by Distillers. This includes a lump-sum payment for a further 367 children affected by Thalidomide in the UK (on the same basis as the initial 62) together with the establishment of the Thalidomide Trust (into which Distillers paid £20 million) to provide 'support and assistance' – including annual grants - to all Thalidomide survivors.
- 2004 Following a campaign led by the Thalidomide Trust's National Advisory Council (NAC), in July the Government announces that compensation payments made to UK Thalidomide survivors will be tax-free.
- 2005 Diageo – formed in 1997 by a merger between Grand Metropolitan and Guinness (who took over Distillers in 1990) – agrees an increased financial settlement with the Thalidomide Trust.
- 2010 In January the UK Government announces that it will provide a Health Grant to all Thalidomide survivors in the UK to help meet the increased health needs caused by their Thalidomide damage, initially for a three year pilot period.

2012 The Health Departments in all four nations of the UK agree to pay the Health Grant for a ten year period until 2022.

The Thalidomide Trust

Background

The Thalidomide Trust is a discretionary trust which was established in 1973 – originally as the Thalidomide Children’s Trust – as part of the £20 million legal settlement between Distillers Company Ltd and 429 disabled children whose mothers had taken Thalidomide in the UK during their pregnancy.

It is a registered charity (number 266220) with the aim of providing ‘relief and assistance’ to people who have disabilities caused by their mothers taking Thalidomide (distributed in the UK by Distillers under the brand name Distaval) during the first three months of their pregnancy.

Since 1973, the Thalidomide Trust has accepted 531 people as beneficiaries, though sadly 64 of them have since died.

Currently the Trust supports 465 beneficiaries .

Role of the Thalidomide Trust

The Thalidomide Trust is responsible for administering two funds - the annual compensation payments funded by Diageo (the company formed by a merger between Grand Metropolitan and Guinness - who took over Distillers in 1990) and the Health Grants funded by the four UK Health Departments.

In addition, the Trust provides information, advocacy and advice on health and broader wellbeing issues to support beneficiaries in maximising their health, independence and quality of life. An important role of the Trust is to support beneficiaries who lack the capacity to make decisions, to ensure that their needs are being appropriately met.

The Trust also funds a small number of research projects in order to fill evidence gaps and develop increased understanding of the needs of its beneficiaries.

How the Trust works

The work of the Trust is governed by 10 highly skilled Trustees who bring a wealth of knowledge and experience to the charity. Three of them are external appointments - by the Lord Chief Justice of England, the President of the Royal College of Surgeons of Edinburgh and the President of the Institute of Chartered Accountants in England and Wales. The remaining Trustees are appointed through a structured recruitment process which directly involves beneficiaries of the Trust.

The Thalidomide Trust’s Trustees and staff work closely with the National Advisory Council (NAC), a group of 12 beneficiaries elected by the whole beneficiary community, to ensure that the Trust is responding effectively to the needs of beneficiaries.

Contacting the Thalidomide Trust

You can contact the Thalidomide Trust by telephone (01480 474074) or email (hello@thalidomidetrust.org)

The Trust has a small group of beneficiaries who act as media spokespeople. If you would like to speak to one of them this can be arranged via the Trust during office hours (Monday to Friday 9am-5pm). At other times please call Mikey Argy on 07875 08432