

**The Thalidomide Trust
United Kingdom**

Response to Conterganstiftung survey, summer 2011

C.I. General Questions

1. How many thalidomide victims live in each country today? How many have already died?

At the date of this report – 522 thalidomide victims have been registered by the Thalidomide Trust since 1973, 51 dead, 471 alive resident mainly in the United Kingdom

2. Which amount overall has been paid out to the victims in individual cases depending on the severity of the damage to date in the respective country (if applicable, depicted based on minor, average, and severe damage)? How much is the average amount? How have the payments been made (one-off payments, recurring payments)?

I have set out the payments schedule for the past 11 years.
The least disabled suffers only minor damage to thumbs,
The most disabled has severe four-limb damage, is blind, and cannot speak.
The “median disabled” has phocomelic arms, and is at the mid-point of all our beneficiaries (and slightly below the mid point on our disability scale).

In 2011 for accounting purposes we have had to transfer some money from the annual grants into the health grants for UK resident beneficiaries, The last health grant will be paid in 2012, subject to reaching a new agreement with the British government after that time.

Extra payments (supplementary grants) were made in 2005 and 2008. The 2005 payment was funded by Diageo plc, the 2008 payment was funded by good investment performance in our trust funds.

Our payments have always been based on annual grants since the start of the Trust in 1974. It would take more time for us to calculate all the payments awarded by this Trust since 1974, but could be done if required. Below I shall supply the original lump sum payments to these three beneficiaries.

In 2011 payments to beneficiaries ranged from:

(Most disabled)	Annual Grant: £49,454	Health Grant: £44,262
(Least disabled)	Annual Grant: £ 2,307	Health Grant: £ 2,065
(Median disabled)	Annual Grant: £23,078	Health Grant: £20,655

In 2010

(Most disabled)	Annual Grant: £51,568	Health Grant: £38,676
(Least disabled)	Annual Grant: £ 2,406	Health Grant: £ 1,805
(Median disabled)	Annual Grant: £24,065	Health Grant: £18,048

In 2009

(Most disabled) Annual Grant: £50,132

(Least disabled) Annual Grant: £ 2,339

(Median disabled) Annual Grant: £23,395

In 2008 (Supplementary grant 50% of 2007 annual grant)

(Most disabled) Annual Grant: £45,014 Supplementary Grant £20,352

(Least disabled) Annual Grant: £ 2,101 Supplementary Grant £ 950

(Median disabled) Annual Grant: £21,006 Supplementary Grant £ 9,497

In 2007

(Most disabled) Annual Grant: £40,704

(Least disabled) Annual Grant: £ 1,900

(Median disabled) Annual Grant: £18,995

In 2006

(Most disabled) Annual Grant: £36,723

(Least disabled) Annual Grant: £ 1,714

(Median disabled) Annual Grant: £17,137

In 2005 (Supplementary grant 70% of annual grant)

(Most disabled) Annual Grant: £51,807 (Includes Supplementary grant)

(Least disabled) Annual Grant: £ 2,417 (Includes Supplementary grant)

(Median disabled) Annual Grant: £24,176 (Includes Supplementary grant)

In 2004

(Most disabled) Annual Grant: £29,929

(Least disabled) Annual Grant: £ 1,397

(Median disabled) Annual Grant: £13,967

In 2003

(Most disabled) Annual Grant: £29,114

(Least disabled) Annual Grant: £ 1,359

(Median disabled) Annual Grant: £13,587

In 2002

(Most disabled) Annual Grant: £28,627

(Least disabled) Annual Grant: £ 1,336

(Median disabled) Annual Grant: £13,359

In 2001

(Most disabled) Annual Grant: £28,149

(Least disabled) Annual Grant: £ 1,313

(Median disabled) Annual Grant: £13,136

Original settlement payments made direct from Distillers to the victims in 1974:

(Most disabled) £39,900 plus accrued interest

(Least disabled) £ 1,862 plus accrued interest

(Median disabled) £18,620 plus accrued interest

3. Is there a dominant interest group or several interest groups of thalidomide victims in the respective country?

All registered UK thalidomide victims are beneficiaries of the Thalidomide trust.

In the UK there is also the Thalidomide Society, with approximately 150 members, some of whom are not victims of thalidomide. This is a membership society not involved in distributing any funds.

C.II. Payments by the respective country

1. Special “compensation” by the respective country for thalidomide victims: are special payments by the country solely for thalidomide victims separate from or in addition to general state benefits 2.)(see below)?

All payments to UK victims following the individual settlements in 1974 have been made through the Thalidomide Trust, and are completely separate from state benefits.

Specific questions:

a) What ongoing regular monetary payments (e.g. monthly, annually) are there and if so, since when?

Not applicable (see answers to question C. I. 2)

b) Which one-off payments or special payments – if applicable, specifically expense-related (building measures, acquisition, etc.) are there and if so, since when and how often? What amount was paid in each case?

There are no such one-off payments for specific purposes. In 2005 an additional payment was made, of 70% of the normal annual grant, to all beneficiaries. In 2008 an additional payment was made, of 50% of the 2007 annual grant to all beneficiaries. In 2010, 2011, and (planned) 2012 health grants are being paid to all beneficiaries at the rate of 75% of the normal annual grant payments for 2010.

c) Is it possible to capitalise recurring payments? If so, do the capitalised amounts have to be repaid by the heirs in event of death of the payments beneficiary before the expiry of the capitalisation period?

The Trust’s system of major grants in effect allows for the short-term capitalisation of annual grants, up to a normal maximum amount of five years’ annual grant payments, recovered over a period of up to 10 years. In normal circumstances unrecovered major grants do not have to be repaid by the heirs if a beneficiary dies.

d) How does thalidomide damage have to be proven? Do the payments necessitate prior examinations and subsequent assessments? Who (which facility, which expert/physician) decides on a potential recognition of thalidomide damage or makes a decision that forms a basis for entitlements?

Prior to January 2007 the only people accepted as beneficiaries of the UK Trust were those who had reached a settlement agreement with the Distillers company (or their corporate successors, Guinness plc and then Diageo plc). Since January 2007, the Thalidomide Trust has its own system for accepting new beneficiaries, and it uses the

evidence of a panel of expert doctors (worldwide), overseen by expert trustees of the Thalidomide Trust.

e) Is there a grading of the payments listed under a) and b) according to the degree of damage or are there flat-rate per capita payments in the same amount?

All payments to Thalidomide trust beneficiaries are graded according to the individual degree of disability, on a scale that ranges from 3,500 to 75,000.

f) Is there a catalogue/criteria for the classification of benefits (e.g. only for non-developed extremities, all different, including organic, body disabilities)? Are these criteria comparable with the points system pursuant to the German Contergan Foundation law and are the same diagnoses compensated in the same way or does the assessment deviate from this (are, for instance, minor disabilities compensated more or less than in Germany)?

The Thalidomide Trust uses a system of grading thalidomide damage developed by the Thalidomide Assessment panel in 1974-1979. There are many more points on this scale (ranging from 3,500 points to 75,000 points) than used in Germany, but it has been independently evaluated by the University of Leeds Medical School and found to be an accurate grading of the differences in disability.

g) Are or were there payments to the parents or carers of thalidomide victims? If so, in what form, to what amount and over which period of time?

In the UK in 1974-197 every couple (parents) with a thalidomide child was awarded £5,000 as a one-off payment. Where the parents were separated they received £2,500 each. This did not continue for later registrations.

h) What is the legal basis of the payments? (Legal provisions, court settlements, fund regulations, etc.)

The legal basis was an out-of-court settlement. The formal offer agreed by the families can be downloaded from this link:
<http://thalidomide.org.uk.dedi2017.your-server.de/archive/download.php?id=4226>

i) Is or was there an exclusion deadline for filing thalidomide claims?

Diageo plc closed their ex-gratia settlement scheme on 31st December 2006, by agreement with the elected representatives of the UK thalidomiders, but claims continue to be accepted directly by the Thalidomide Trust

j) Are changes/increases in the payments planned?

Yes. The basic annual grants for Thalidomide Trust beneficiaries are planned to be increased by a rate greater than the increase in the UK cost of living up to April 2022, and thereafter to be increased in line with increases in the UK cost of living.

k) Are the payments subject to taxation? If so, to what extent?

No. All UK Trust payments to beneficiaries are exempt from the payment of tax. The relevant law can be seen on this link:

http://www.legislation.gov.uk/uksi/2004/1819/pdfs/uksi_20041819_en.pdf

l) Are there specialised facilities/care centres?

No. There are a few centres where the doctors have special expertise with aspects of thalidomide care, but the centres themselves are not dedicated to thalidomide.

2. General Social Benefits from the respective state to thalidomide victims (in addition to the special payments under 1.):

Are there social benefits in the respective country comparable to those in Germany?

I am sorry, I do not know the German social benefits system and cannot give a comparison. Apart from the social benefits available to any person in UK (free health care, unemployment benefits, housing benefits) disabled people receive Disability Living Allowance, at rates which vary according to their disability, from £19.55 to £125 per week:

http://www.direct.gov.uk/en/disabledpeople/financialsupport/dg_10011925

If people are in receipt of Disability Living Allowance they are also entitled to a rebate on their Council Tax (property tax).

In addition to this, they can receive carers in their homes, for varying numbers of hours per week, according to their disability needs paid by state funds.

For those who have been in employment, they might also be entitled to incapacity benefit, and there are schemes to provide disabled people with help in employment, under the Access to Work scheme:

http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347

Disabled Facilities grants are available to help adapt homes for the needs of disabled people, and cover the cost of things like ramps, special toilets, and bathroom conversions..

The Motability scheme works with the Mobility component of Disability Living Allowance to help disabled people finance cars and adaptations:

<http://www.motability.co.uk/main.cfm>

Specific questions:

a) If so, do these social benefits meet the minimum of basic requirements defined in the respective country or do they exceed them?

I am not aware of a suitable national definition of needs

b) Do the special benefits from the state (see 1. above) and assets that are saved from these remain unaffected in the granting of general state benefits or are they offset? If so, to what amount?

Some state benefits for disabled people (care, housing) will be offset if the person has cash savings above a certain figure (£16,000 capital for housing benefit), but they do not take into account payments from the Thalidomide Trust (or Disability living Allowance).

c) To what amount are income and assets not taken into consideration in the granting of state benefits?

Income can be taken into account against unemployment and housing benefits, as also capital assets (see answer above), but this does not apply to payments from the Thalidomide Trust.

d) Is there the option of protecting against individual incapacity for work due to the thalidomide damage existing before the start of the policy?

This does not apply in UK (state support is not based on insurance)

e) Is there the option of private accident insurance due to the thalidomide damage despite the existence of the damage or a need for nursing care arising from this at the start of the policy?

This does not apply in UK (state support is not based on insurance)

f) Is it possible to take out life insurance despite the thalidomide damage/need for nursing care?

It is possible to take out life insurance. We do not know about insurances for nursing care.

g) Is there a special/separate old-age (retirement) pension for thalidomide victims? If so, how is it organised?

Thalidomide victims are entitled to the same old age pensions as anyone else in UK. Details can be found at the following link:

http://www.direct.gov.uk/en/Pensionsandretirementplanning/StatePension/DG_183759

C.III. Payments by the perpetrators of the thalidomide disabilities

Are or were there compensation payments, compensation, special payments or support for the victims? If so, in what form and in what amount? Are such benefits planned?

See answer to question C.I. 2

C.IV. Payments by third parties (with the exception of the German Contergan Foundation for Disabled people)

Is or was there compensation, special payment(s) or other support for the victims by private companies (with the exception of the perpetrators) and/or by organisations? If so, in what form and in what amount? Are such benefits planned?

No.