

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 084320.