

# The Thalidomide Trust

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## Health & Wellbeing Trustee

### Candidate Information Pack

October 2024



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# About The Thalidomide Trust

The Thalidomide Trust, is a registered charity, supporting a unique community of 426 beneficiaries, now all aged in their 60s, born with disabilities as a result of their mother taking the drug, thalidomide, during pregnancy. Their physical disabilities include limb damage, hearing and visual impairment, brain and sensory impairment and damage to internal organs. They are a remarkable group of people, who have achieved a great deal despite often living with extreme levels of disability.

Our beneficiaries are all a similar age and experience similar issues and challenges – but they are definitely not all the same. They have very complex and varied needs which are increasing as they age, and we are able to apply the wealth of data we gather through our structured programme of Holistic Needs Assessments (HNAs) to ensure we understand and respond to their evolving needs.

Our work is overseen and directed by an impressive Board of Trustees who bring a wealth of experience and expertise across the fields of finance, governance, health, research and social care.

## **Our Vision:**

That each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time.

## **Our Ethos:**

We put the beneficiary community at the heart of everything we do. We are supportive, non-judgemental, inclusive and fair - and are committed to beneficiary empowerment and maintaining effective two-way communication with beneficiaries.

## **Our Strategic Goals:**

1. To ensure the Trust's income is secure, financial risk is effectively managed and adequate funding is available to meet the increasing needs of beneficiaries as they age.
2. To apply the Trust's resources strategically, effectively and equitably (in order to achieve our vision).
3. To ensure that all beneficiaries have access to the best possible information, advice, advocacy, services and support – both within and outside the Trust – as they age and their physical and mental health needs increase.
4. To ensure effective (two-way) sharing of knowledge and learning for the benefit of the beneficiary community and for wider public benefit.
5. To ensure that the individual beneficiary's needs remain paramount, even when third parties (families, carers, representatives) have a role in acting on their behalf.



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# What We Do

## How We Work:

Our beneficiaries are at the heart of everything we do and they inform and shape the Trust's activities.

## History of Thalidomide:

Thalidomide was developed by the German company Chemie Grünenthal in 1954 and marketed as a sedative in the UK in 1958, notably for treating morning sickness in pregnant women. It was later linked to severe birth defects, leading to its withdrawal in 1961.

The Thalidomide Trust was established in 1973 after a £20 million settlement with Distillers, the UK distributor. Over the years, additional compensation was secured, and Diageo, which acquired Distillers in 1990, has continued to support survivors.

The Thalidomide Trust administers two funds set up to support people affected by thalidomide:

- Annual compensation payments– funded by Diageo
- Health Grants– funded by the four UK Health & Social Care Departments

## But our team doesn't just distribute grants, we do so much more:

- We offer a unique holistic health and wellbeing service to support beneficiaries to achieve the best possible health, independence and quality of life
- We provide emotional support and understanding
- We support beneficiaries who don't have the capacity to make decisions to ensure their needs are met
- We provide support with finances and future planning
- We provide information and advice to professionals who work with beneficiaries to ensure they understand and respond effectively to their needs
- We encourage and support peer to peer support through trained beneficiary volunteers
- We gather data and commission research to ensure we understand and can continue to meet the needs of beneficiaries



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# Person Specification

We are looking for an experienced and credible senior health or social care professional with a strategic approach and knowledge of the current challenging environment - ideally in respect of disability and ageing - to join our Board of Trustees\*. Our Vision is that 'each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time' and, as they enter the next phase of their lives and as their needs grow ever more complex, you will play an important role in ensuring we provide the best possible future for them.

## Essential:

- Experience of operating in a senior role in a health and/or social care environment - this could include policy, systems leadership, or practice environment – ideally in respect of disability and ageing.
- Good current knowledge of health and social care environment and an understanding of the implications for beneficiaries of the Thalidomide Trust.
- Good current understanding of health and social care provision and the interface between health and social care.
- A high external profile and strong links with professional networks.
- Commitment to the aims of the Thalidomide Trust and an understanding and acceptance of the legal duties and responsibilities of a charity trustee.
- Commitment to safeguard the reputation and values of the Trust and ensure resources are used wisely and in the best interests of all beneficiaries.
- Team player with a collaborative approach and experience of effective partnership working with service users.
- Ability to make sound independent judgments and decisions in the best interests of all beneficiaries.
- Able to demonstrate integrity, strategic vision, accountability and a willingness to speak their mind, alongside a caring, empathetic and non-judgemental attitude.
- Good understanding of safeguarding, empowerment and inclusion.
- Willingness and ability to devote the approximately 20 days (plus travel time) per annum to the Trust – and specifically be available to attend three full day Board meetings, at least two half-day Health & Wellbeing Committee meetings and one beneficiary event each year.

## Desirable:

- Understanding of the needs of people ageing with disabilities and the interface between frailty and ageing.
- Understanding of the issues around capacity (including fluctuating capacity) and the legal framework to support them.
- Understanding of the psychosocial aspects of health and ageing





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## How to Apply

If you are interested in the role and would like to apply for the position of Health & Wellbeing Trustee, please provide us with:

- An up-to-date CV
- A supporting statement of no more than 2 sides of A4, detailing why you would like to be considered, your relevant experience and expertise and what you think you can bring to the role.

All applications are being handled by our recruitment partner, Trustees Unlimited (part of the Russam group).

**All applications should be sent to [applications@trustees-unlimited.co.uk](mailto:applications@trustees-unlimited.co.uk) with your full name and The Thalidomide Trust in the subject heading.**

If you have any difficulty uploading your application or if you would like to have an informal and confidential discussion about the role, alternatively please contact Melissa Baxter:

[melissa.baxter@russam.co.uk](mailto:melissa.baxter@russam.co.uk) | 07789 985 229

**Closing date for applications:** Monday 28th October 2024 (close of play)

**Interviews with The Thalidomide Trust:** w/c 11th November 2024

*We hope you will join us on our journey.*

